

# **RESPECTFUL MATERNITY CARE IN SANTA CRUZ COUNTY, CALIFORNIA**

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CINDY ALIZA STEIN, CNM, MSN, MPH

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Committee:  
Maureen Shannon Committee Chair  
Jan Brunson  
Carmen Linhares  
Deborah Mattheus  
Karen Tessier

**Keywords:** maternal mortality, maternal death, facility-based maternity care, barriers to obstetric care, maternal morbidity, maternal near-misses, disrespectful maternity care, respectful maternity care, burnout, midwife burnout, compassion fatigue, human rights and birth, three delay, three-delays model.

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## **Abstract**

**Background:** In the global setting, despite access to lifesaving care in facilities that serve women during childbirth, many women delay or avoid using these services, as evidenced by vast amounts of literature on the topic. This has even proven true when controlled for variables that serve as obstacles to obtaining the care that they need. Global stakeholders have acknowledged the presence of disrespect and abuse (D&A) by staff within health facilities as a deterrent to women seeking lifesaving maternity services; the association between how respectfully a woman is treated during childbearing with how likely she is to utilize maternity services in the future. The movement to eliminate D&A in the maternity setting has resulted in the development of Respectful Maternity Care (RMC) as a model to combat this issue. However, a standardized definition of what respect means to childbearing women has never been established, making implementation of RMC universal standards and interventions difficult. This study was aimed at beginning to define what women consider respectful care to be so that minimum standards can be applied with an eye towards training staff, creating regulations that encourage or require RMC, or other potential interventions aimed at better serving women during childbirth.

**Method and Findings:** A qualitative descriptive study design was used in order to hear detailed accounts of women's experiences and perceptions about respect. This emic approach allowed for an analysis of the experiences of participants while an iterative process was used to analyze the data resulting in codes, categories and themes via content analysis. Using semi structured interviews that explored themes in respectful maternity

care through the lens of ten women who had recently given birth in Santa Cruz County, California. Recruitment stopped once saturation was achieved. Five themes emerged from the analysis: 1) Needs Were Met In a Timely Manner; 2) Care is Patient Centered; 3) Overall Feelings of Kindness; 4) Caregivers Are Experts; and 5) The Environment is Safe. The working definition of respect that can be derived from this study and its resulting themes is, “Respect in the maternity setting is a multivariate concept based on women feeling well cared for by health workers based on their attitudes and actions: attentiveness, a high level of knowledge, kindness, a focus on patient preference, and providing a safe environment to put women at ease.”

**Limitations:** Due to the homogenous nature of the study sample, saturation was reached at ten, a small sample size. Descriptions may be limited in that they are not generalizable to other populations. Also, contributing factors such as experiences during the prenatal period were not discussed in interviews.

**Conclusions:** The results of this small study indicated that women experiencing childbirth consider respectful care to involve attitudes and behaviors of maternity staff that encompass treating the women with kindness, providing care that is based on current evidence to ensure their and their infants’ safety, being attentive to their needs in a timely manner, and including them in conversations about plans of care while considering their desires reflecting a patient-centered approach to care.

**Keywords:** maternal mortality, maternal death, facility-based maternity care, barriers to obstetric care, maternal morbidity, maternal near-misses, disrespectful maternity care, respectful maternity care, burnout, midwife burnout, compassion fatigue, human rights and birth, three delay, three-delays model.

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## **CHAPTER 1. INTRODUCTION**

In the global setting, the overall progress in reducing maternal mortality has been largely unsuccessful despite decades of focus on improvements in health systems' infrastructures. (Prata, Passano, Sreenivas, & Gerds, 2010). Of particular note is the lower than expected utilization of potentially lifesaving care by skilled birth attendants consistently across the world, even when controlling for financial, cultural, and geographic barriers (Freedman & Kruk, 2014; Kujawski et al., 2015). Global stakeholders have acknowledged the presence of disrespect and abuse (D&A) by staff within health facilities as a deterrent to women seeking lifesaving maternity services; the association between how respectfully a woman is treated during childbearing with how likely she is to utilize maternity services subsequently has been well described in recent literature (D'Ambruoso, Abbey, & Hussein, 2005; Kujawski et al., 2015; Vogel et al., 2015). Because high quality care provided by skilled attendants is known to save lives during childbearing, it is particularly alarming that women intentionally delay or avoid these services even when they are available in their communities (Ith, Dawson, & Homer, 2012). The significance of these decisions exists on a continuum ranging from high maternal death rates on the extreme end, to the economic consequences of growing patient dissatisfaction within maternity care in the United States (US) (Henderson & Petrou, 2008). The movement to eliminate D&A in the maternity setting has resulted in the development of Respectful Maternity Care (RMC) as a model to combat this issue. However, a standardized definition of what respect means to childbearing women has never been established, making implementation of RMC universal standards and interventions difficult.

This chapter presents a brief summary of the significance of the problem in order to lay the groundwork for the study's purpose and design, a brief summary of the relevant literature indicating why this warrants study, the research questions, methodology, analysis of the data, and discussion about the results of the study.

### **Background and Significance**

High quality care provided by skilled birth attendants is known to save women's and infant's lives, therefore, it is particularly alarming when women intentionally delay or avoid seeking needed care due to negative past experiences, especially when maternity services are available in their communities (Bohren, Hunter, Munthe-kaas, Souza, & Vogel, 2014; Essendi, Mills, & Fotso, 2010; Ith et al., 2012). As Freedman and Kruk (2014) explain, D&A exists on a wide spectrum and has been documented as the result of a myriad of factors. Overburdened workforces, lack of sensitivity within training programs, and ethnic, socioeconomic, and cultural discrimination all serve as contributors (Flávia, Lucas, Diniz, & Schraiber, 2002; Jewkes, Abrahams, & Mvo, 1998). Disrespect and abuse can also partly be attributed to the stress and burnout among maternity staff that routinely work without the resources they need. This issue was clearly stated by Halperin et al. "the importance of developing innovative resources to assist midwives in coping with the complex realities of practice so that they can feel nurtured and valued." (Halperin et al., 2011, p 392). Additionally, literature suggests that staff who are experiencing high stress and low job satisfaction have worse patient satisfaction ratings (Vahey, Aiken, Sloane, Clarke, & Vargas., 2004).

While general acknowledgment that RMC could serve as a solution in the future, the research is scant and only encompasses prevalence, causes, and consequences of



D&A by health workers (Abuya et al., 2015; Freedman & Kruk, 2014; Snow et al., 2011)

Most of the funding committed to ameliorating this emerging issue has been devoted to advocacy at the top levels within the context of reducing maternal mortality rates in low resource settings (Freedman, 2001; White Ribbon Alliance, n.d.). Even less has been published on these issues in the context of developed nations where economics rather than mortality rates sits at the forefront of conversations about health care systems. Much of what does exist takes the form of staff retention studies (from the angle of stress and burnout as causes for poor patient treatment and eventual recidivism) and the growth in the homebirth movement as a consequence of disrespect in facilities (Boucher, Bennett, McFarlin, & Freeze, 2008; Mollart, Skinner, Newing, & Foureur, 2013). Training programs and the development of guidelines to integrate respect into maternity services such as the US Agency for Aid and Development (USAID) RMC Toolkit have emerged from this limited body of literature and may offer some promise that behavior change could eventually influence consumer utilization rates (Reis et al., 2012). Still, exploration to develop a standardized definition of what respect means to the women who will ultimately make decisions about where and with whom to give birth should inform developing interventions and policies.

### **Problem Statement**

Acknowledging and introducing respect into service delivery in the maternity setting shows promise in eliminating D&A (Reis, Deller, Carr, & Smith, 2012; The White Ribbon Alliance for Safe Motherhood, 2011; Warren et al., 2013). However, there is a significant gap in the literature in terms of determining an exact explanation of what respect means to women. It is clearly necessary, therefore, to explore what respect means

in order to operationalize a definition, as having this would serve as the first step in creating interventions to yield behavior changes among health workers resulting in RMC.

### **Purpose of the Study**

The purposes of this study were to explore what women who have recently given birth consider respectful care by maternity workers to be; what their experiences of respectful care were during childbirth and the immediate postpartum period; and how important respectful care was to them in terms of their ongoing health-seeking behaviors.

### **Research Questions**

In order to address the purposes of this study, the following research questions were asked:

1. What do women who have recently given birth consider to be respectful care by maternity workers?
2. What were the experiences of respectful care of women who have recently given birth?
3. What are women's thoughts about the importance of experiencing respectful care in their future decision-making about seeking and accessing maternity services?

### **Method**

An extensive literature review revealed that there is an absence of studies that sought to define respect by health workers within the maternity setting. The significance of this is seen in literature that addresses how women's perceptions of respect (and conversely disrespect and abuse) heavily influence their decisions about whether or not to seek potentially lifesaving maternity care with skilled birth attendants in the future. Therefore, the research questions focused on women's experiences, perceptions, and thoughts about respect and respectful care during a particularly vulnerable period in

childbearing (intrapartum and the immediate postpartum period) in order to develop a beginning definition of respect within maternity care that could be universally acceptable to women despite the obvious individual factors associated with the concept of respect in general.

A qualitative descriptive study design was used to address this gap in knowledge. This approach was used in order to hear detailed accounts of women's experiences and perceptions about respect. This emic approach allowed for an analysis of the experiences of participants using an iterative process to analyze the data resulting in codes, categories and themes.

### **Study Sample**

The study included ten women who had given birth within the six months prior to the interview so that they could provide 'fresh' details about their experiences giving birth. The inclusion criteria were as follows: (a) women who lived in and received all of their prenatal and intrapartum care in Santa Cruz County, California; (b) gave birth in the previous 6 months; (c) did not have life threatening pregnancy or birth complications; (d) gave birth to infants without anomalies or life-threatening conditions; and (e) agreed to participate in the study. They were recruited from within voluntary "New Parents" groups that are offered in the community free of charge.

### **Setting**

The study was conducted in Santa Cruz County, California. The participants were women who had attended a breastfeeding and postpartum support group located at the Sutter Maternity and Surgery Center in Santa Cruz.

## **Recruitment**

Women were recruited from within the “New Parents” group, which is offered at the Sutter Maternity and Surgery Center in Santa Cruz, California. The support group takes place several times a week as a drop-in support group led by registered nurses and certified lactation consultants. These groups serve women free of charge regardless of where they gave birth and have historically attracted women from diverse backgrounds in terms of age, parity, and socio-economic status. The hope was that this study would draw participants who roughly mirrored the ethnic makeup of childbearing women in Santa Cruz County in general (Table 1). While there was a small amount of diversity in the participant group, it did not reflect the overall breakdown of the county.

The primary investigator spent five minutes at the start of several sessions of the New Parents’ group explaining the study and offered a copy of the consent form and contact information. Any questions were answered and interested women were asked to contact the investigator directly in order to participate.

Recruitment and enrollment of participants continued until the data analysis indicated that saturation had been achieved (i.e., when there were no more new codes, categories or themes emerging from the interview content).

## **Protection of Human Subjects**

Permission to implement this study was obtained from the University of Hawai‘i at Mānoa (UHM) institutional review board (IRB) and the Ethics Review Board at the state office of Sutter Health Services. Confidentiality of women was maintained at all times. The interviews took place in a private location of the participant’s choosing. Informed consent was obtained before the interviews began and the participant was

afforded time to ask questions or discuss anything about the study. Each participant was assigned a study identification number that was used for the entire study from data collection through analysis and reporting. All data collected as part of the study was kept on the researcher's password-protected laptop in an encrypted file and accessible only by the researcher. A professional transcriptionist was employed to transcribe the interviews. The transcribed interviews were kept on an encrypted external hard drive, and were destroyed at the completion of the study along with all other research materials according to IRB requirements.

### **Data Collection**

Data collection was completed during a single visit with each participant meeting with the researcher on an individual, face-to-face basis where a semi-structured interview was done. An interview guide was used to pose the research questions and the use of prompts to elicit additional information during the interview. Data collection continued until saturation was achieved.

### **Data Analysis**

A qualitative content analysis of each interview was completed. This included a proscribed method of unitizing, sampling, coding, reducing, inferring, and narrating the data to transform it into conclusions and themes. The researcher also analyzed any field notes written during the interviews. Trustworthiness was ensured through establishing an audit trail, employing member checking to verify the researcher's interpretations, and having a specified number of interview transcripts independently reviewed by a content expert familiar with this methodology. An iterative process was used so that when a new code or category was determined, previously analyzed interview transcripts were

reviewed to assess for the new codes applicability to those data. Final interpretation of the analysis included contacting some participants to confirm that the researcher's interpretation was consistent with what their experiences and perceptions were (i.e., member checking).

## **Results**

A total of fourteen women volunteered, ten of whom met inclusion criteria to participate. These ten women were consented and semi structured interviews were completed using the IRB approved research question guide. All of the women lived and gave birth in Santa Cruz County, California in the six months prior to when the interviews took place. They all had given birth to their first singleton, full term babies without any major complications. None of the women had received any portion of their prenatal, intrapartum, or postpartum care by the interviewer. Five themes emerged from the study: *1) Needs Were Met In a Timely Manner; 2) Care is Patient Centered; 3) Overall Feelings of Kindness; 4) Caregivers Are Experts; and 5) The Environment is Safe.*

## **Limitations**

The fairly homogenous population that this study attracted can lead to limitations of generalizability of the results. Not only was the sample group not exactly reflective of the ethnic makeup of Santa Cruz County, but also it consisted of women who self-selected to attend the meetings where recruitment took place. The women who participated generally all had positive experiences as the “birth culture” in Santa Cruz County already

leans somewhat towards being patient-centered. Further, the facilities in the study area are well staffed and could be considered “high resource” facilities. None of the women who participated delivered at home. Finally, the sample size was small due to the aforementioned reasons as saturation was reached fairly quickly.

## **Conclusion**

Five themes emerged as a result of the content analysis process. These led to a working definition of respect which is, “Respect in the maternity setting is a multivariate concept based on women feeling well cared for by health workers based on their attitudes and actions: attentiveness, a high level of knowledge, kindness, a focus on patient preference, and providing a safe environment to put women at ease.”

## **CHAPTER 2: LITERATURE REVIEW**

This chapter will present the results of literature reviews that were conducted about disrespect and abuse (D&A) in maternity care, and theoretical frameworks that served to guide previous research that addressed D & A of childbearing women. Additionally, in order to work towards a solution for D & A, literature available on the general concepts of respect (and its associated concept of compassion) was reviewed and will be presented in this chapter.

### **Defining Disrespect and Abuse by Health Workers in the Maternity Setting (D&A)**

Pregnancy and childbirth are seen as a rite of passage within the context of most cultures and typically serve as one of the defining experiences in a woman's life. Unfortunately, for many women this rite is often marred by their experiences with disrespect and/or abuse (D&A) by providers when seeking services at health facilities. A significant number of preventable obstetric complications occur because of a prior negative experience with the healthcare system that can contribute to a woman delaying (or altogether avoiding) the decision to seek care at a facility where lives can be saved (Bowser & Hill, 2010; Jammeh, Sundby, & Vangen, 2011; The White Ribbon Alliance for Safe Motherhood, 2011). These negative experiences of D&A can also leave a lasting impression on women that can spread to family members and communities as women retell their negative experiences to others, thus affecting health-seeking behaviors of increasing numbers of women (Bowser & Hill, 2010). Conversely, women who feel that they are treated well by healthcare staff can provide positive marketing for health care services and increase return visits for these women in the future. A systematic review of attitudes and behaviors in maternity care found that, "women experiencing positive



attitudes and behaviors were more likely to decide to return to a facility than those experiencing negative ones “ (Mannava, Durrant, Fisher, Chersich, & Luchters, 2015, p. 6). While this may seem intuitive, it becomes even more consequential for women in childbirth, who represent a sector of the population that must often make health-seeking decisions that can have life-and-death outcomes linked to them. The choice to avoid or delay facility-based care is often made independently of the traditional variables that serve as healthcare barriers. Literature shows that when transportation to facilities and costs of services do not pose obstacles to care, women still do not seek care at the target rate. McConville (2014) refers to the “ghost hospitals” which are fully stocked with lifesaving drugs and equipment; however, women do not access these services (Mcconville & Alliance, 2014). Disrespect and abuse should be viewed as significant issues in both global and domestic settings since underutilization of available services can be found in both settings. The White Ribbon Alliance (2010) summarizes:

A woman’s relationship with maternity care providers and the maternity care system during pregnancy and childbirth is vitally important. Not only are these encounters the vehicle for essential and potentially lifesaving health services, women’s experiences with caregivers at this time have the impact to empower and comfort or to inflict lasting damage and emotional trauma, adding to or detracting from women’s confidence and self-esteem. Either way, women’s memories of their childbearing experiences stay with them for a lifetime and are often shared with other women, contributing to a climate of confidence or doubt around childbearing. (The White Ribbon Alliance for Safe Motherhood, 2011, par 2).

Complicating the issue is the elusive definition of what exactly constitutes D&A.

Freedman and Kruk (2014) describe these and the complexities associated with them:

To define D&A, which is essential both for measurement and for accountability, is a complex challenge. The “legitimate right to and expectation for equitable, high-quality, safe, and respectful care” the Lancet Midwifery Series endorses, although straightforward as a statement of aspiration for the health system, is

harder to discern and use as a principle for research and intervention on the ground. Practices that to the outside advocate or trained observer seem unambiguously disrespectful or abusive are often normalized by patients or providers, or both. The expectations, meanings, intentions, and rationalisations that surround a sharp slap and angry word while a woman struggles to push in the final stages of labour remind us that health systems often reflect the deeper dynamics of power and inequity that shape the broader societies in which they are embedded (p. 1).

The approach to define D&A has largely been from the human rights perspective with social, gender, and health equality as driving forces in creating policies and initiatives for professional organizations to sign on to and adopt for standardization purposes. Through this perspective, a clarification of the types of D&A women endure during childbirth were initially described in a landscape report funded by USAID and completed by Bowser and Hill in 2010. The report titled, *Exploring Evidence for Disrespect and Abuse in Facility-Based Childbirth* gained the attention of key stakeholders and resulted in a categorization, which is generally now accepted as the standard typology. The categories include: (a) physical abuse, (b) non-consented care, (c) non-confidential care, (d) non-dignified care, (e) discrimination based on patient attributes, (f) abandonment of care, and (g) detention in facilities (Bowser & Hill, 2010). These were eventually used as the building blocks for the White Ribbon Alliance to create the “Universal Rights of Childbearing Women” which serves as a charter for advocacy and policy purposes (White Ribbon Alliance, n.d.) (Table 1). However, as Freedman et al. (2014) point out, “These categories describe types of disrespect and abuse that happen in health facilities, but do not define it in terms of the characteristics of health-care provider behaviour, facility conditions or other factors that could be construed as disrespectful and abusive” (p. 915). They propose further study looking deeper into three specific areas: (a) behavior that, by consensus, constitutes D&A, (b) subjective experience (where the content of the

study discussed in this dissertation will fall), and (c) intentionality (p. 917).

A study in 2015 also looked at harmonizing a definition of D&A by examining data from 13 Kenyan facilities where instances of negative behaviors by health workers were elicited from patient interviews and observation of the maternity units (Abuya et al., 2015). They created categories based on the *Universal Rights of Childbearing Women* and then constructed a system to map subcategories into domains. The negative behaviors were divided into groups based on four key dimensions: (a) human rights law, (b) domestic law, (c) ethical codes, and (d) local consensus on behaviors. The group then created exit surveys based on the preliminary definition and validated the tool using qualitative interviews to identify gaps in the construct map. They then administered the instrument to 75 women to check reliability. Additionally, two weeks after delivery, they followed up with 25 of the women who had experienced disrespect or abuse and 25 women who did not. They deduced that, “Women’s previous experiences of disrespect and abuse at healthcare facilities for childbirth or other visits may ‘normalize’ disrespectful or abusive care. Women expect such behavior and therefore do not think it is abnormal, illegal, or ethically wrong” (Abuya et al. 2015, p. 11).

A comprehensive review of several databases used a predetermined search strategy to identify qualitative, quantitative, and mixed-methods studies on the mistreatment of women during childbirth across all geographical and income-level settings. The study focused specifically on the mistreatment of women by health workers while receiving maternity care refined the definition of D&A by looking at 65 studies in 34 different countries and categorized types of abuse into seven domains: (a) physical abuse, (b) sexual abuse, (c) verbal abuse, (d) stigma/discrimination, (e) failure to meet standards of care, (f)

poor rapport between woman and providers, and (g) health system conditions and constraints (Bohren et al., 2015). Ultimately, they concluded that,

While different countries, organizations, and authors have adopted different terminology (such as “obstetric violence,” “dehumanized care,” and “disrespect and abuse”) to describe the phenomenon discussed in this review, we have proposed ‘mistreatment of women’ as a broader, more inclusive term that better captures the full range of experiences women and health care providers have described in the literature (p. 21).

In an article titled *You can drop dead*, the authors define bullying in the midwifery context as, “behavior that is perceived as uncaring, cold, callous, threatening, abuse or aggressive: the midwife in a position of authority abuses and exerts power over the woman who is in the more vulnerable position” (Dietsch, Shackleton, Davies, Mcleod, & Alston, 2010, p. 54). Existing literature points to the fact that D&A mirrors domestic violence in that it takes form as verbal, physical, and sexual in nature, although, it also refers to excessive medical treatment, unnecessary (and invasive) procedures, and forced immobilization (Lucas d’Oliveira, Diniz, & Schraiber, 2002). Specific examples of D&A include yelling, insulting a woman’s cleanliness, rudeness, slapping, lack of privacy, absence of confidentiality, no provider support in labor and refusal to allow women to bring a labor companion with them (Bowser & Hill, 2010). In Nigeria, disallowing women to remain clothed, as well as ridiculing their parity, their pain tolerance, and poverty level were deterrents to returning for subsequent care (Olusanya, Alakija, & Inem, 2010). Non-consented care in the form of cesarean procedures, sterilization, augmentation of labor, and episiotomy has been widely documented, as have abandonment in labor and discrimination by providers. The idea of a woman being detained if she or her family are unable to pay the health care bill has also deterred

women from seeking services because of these real experiences and perceptions of the medical system (Bowser & Hill, 2010; Oyerinde, Harding, & Amara, 2012).

### **Influencing Factors of D&A**

A systematic review by Mannava (2014) included 81 articles looking at D&A and concluded that there are four main factors influencing negative behaviors by maternity health workers. The antecedents that the authors found fell within the following categories: (a) organizational, (b) individual, (c) provider-patient relationship, and (d) patient attitudes and behaviors (Mannava et al., 2015). Similarly, in Janevic et al.'s 2011 study, racism emerged from a Grounded Theory approach of Romani women in the Balkans that included institutional, personally mediated, and internalized forms of racism as root causes of the D&A that women suffered (Janevic, Sripad, Bradley, & Dimitrievska, 2011). Organizational level factors included such issues as heavy workloads for staff, long hours of work, low salaries, poor collegial relationships, poor training and lack of physical space to work. In addition, one study from Kenya found that higher incidences of verbal abuse of patients by nurses/midwives occurred on night shifts (Abuya, Warren, et al., 2015). Individual level issues included patient attributes (age, marital status, etc.) and socio-economic prejudices. A qualitative study from Ghana provides the following example of D&A, "in the hospital if a woman goes there to deliver and she did not buy the baby's clothes and things, the nurses will be insulting her" (Moyer et al., 2014, p. 265). Provider-patient relationship issues include the hierarchy prevalent in many medical settings where the health worker feels compelled to reinforce their superiority, while patient attitudes and behaviors refer to things like being "non-compliant", showing up late, verbal abuse by family members, wanting to deliver in

various positions, and transfers from failed homebirths (Mannava et al., 2015). d'Oliveira (2002) explains further,

Forms of structural violence experienced by staff can affect their behavior toward patients. Heavy workload, long hours, inadequate equipment or facilities, and personal danger can demoralize and traumatise staff and lead them to take their frustration out on patients. Violence within healthcare settings often reflects dynamics that are broadly prevalent in society. In societies in which violence is highly prevalent at home, in the streets, in schools, the use of violence in healthcare services may be seen as an extension of generally high levels of violence in society” (p. 1683).

Other antecedents to D&A that have been well documented in the literature fall within similar themes. Staff stress, burnout and training that perpetuates poor treatment of women are frequently to blame for D&A existing in facilities with high frequency (d'Oliveira et al., 2002). The low status of women in many societies in addition to gender inequality at large both have created a baseline of structural violence which can be magnified in the childbearing setting and lead to D&A (Sadler et al., 2016). The author, d'Oliveira (2002) explains,

In many societies, women have a low status and are seen as needing discipline and control for their own good. These can be interpreted in the healthcare setting as legitimizing use of violence by staff to control female patients' behavior” (p. 1683).

Kim and Motsei's 2002 study investigated nurse's perceptions of gender-based violence in South Africa, one participant stated, “Women are very tough. Even if you hit them, they can still come back and tolerate the situation. That's how they are made” (Kim & Motsei, 2002, p. 1247).

Much of the literature exploring the link between burnout, stress levels, and emotional exhaustion of healthcare workers leading to maltreatment of patients is borrowed from other specialties. Social workers, nurses and other health professionals

often face high stress levels and high workload burdens that contribute to compassion fatigue and emotional exhaustion (Lombardo & Eyre, 2010). This is significant because one of the features of burnout is its strong correlation to losing compassion for clients (Mollart, Skinner, Newing, & Foureur, 2013). While patient and community experiences and perceptions of D&A in facility-based maternity care are difficult to evaluate in terms of prevalence, burnout and stress among midwives can be more easily measured. Since there are several validated self-reporting tools for stress and burnout among healthcare workers, and because rates of healthcare workers leaving the profession can be measured quantitatively, a clearer picture has emerged. One useful tool to assess stress and burnout that appears with regularity in nursing and midwifery literature is the Maslach Burnout Inventory Human Services Survey (MBI HSS), which identifies features of emotional exhaustion (EE), depersonalization (DP), and personal accomplishment (PA) (Maslach, Jackson, & Leiter, 1996).

Using the MBI HSS, one study found that midwives taking care of women with higher levels of acuity suffered more symptoms of burnout (Mollart et al., 2013). The concept of taking care of ‘hard patients’ (which can refer to either medically, emotionally or psycho-socially complicated women) as a predictor of stress levels in healthcare providers has been documented in the midwifery profession (Mollart et al., 2013). A literature review looking at various studies that address emotional stress and secondary PTSD among midwives based on the acuity of patients they care for determined that the inherent emotional stress of the profession of midwifery, caused both by the nature of the relationships between the provider and the client as well as the ‘life and death’ events they experience, can have harmful emotional consequences for midwives and their ability

to provide adequate care (Leinweber & Rowe, 2010). Poor outcomes have even more profound effects on the midwife, which one participant in a qualitative study illustrates:

The difficulty is both physical and emotional, your blood boils. . . and there is no blood that goes to the brain, your whole body is paralyzed from shock. I was totally in shock. I felt strong pain physically. . . I wasn't able to eat. . . weakness, terrible hand tremor. . . palpitations, dizziness. I had a headache and physical pain in my stomach and feet (Halperin et al., 2011)

Burnout and stress are also strongly rooted in the literature in the context of midwives feeling undervalued and receiving low compensation for the mentally and physically demanding work that they do. One study among Croatian midwives indicated that 76% of midwife participants felt these were factors contributing to their high work stress levels (Knezevic et al., 2011). These issues can be seen as a recurring theme across the body of literature on stress and midwives (Halperin et al., 2011; Hassan-Bitar & Narrainen, 2011).

Poor interpersonal relationships between facility staff create circumstances where maltreatment of patients is more likely (Vahey et al., 2004). Midwives interviewed in a variety of research projects discussed the hierarchy that exists within the typical patriarchal medical model and how it affects them at work. With a primarily female workforce, midwives are often subjected to the same gender stratification and social inequalities that their clients face both at work and within the communities in which they live. A descriptive qualitative study of midwives in the Palestinian Territories found that a common reason for low morale was the humiliation and powerlessness the midwives were subjected to by the (mostly male) doctors they worked with (Hassan-Bitar & Narrainen, 2011). Midwives, who are, by definition, charged with empowering women through the care that they provide, are unable to do that if they themselves are subjected



to dismissive and degrading treatment. Taken a step further, this concept can extend to real or anticipated poor treatment from patients or their families and communities as the result of poor birth outcomes that can also contribute to low morale. One midwife explains,

The baby was born with defects. The mother blamed me since I delivered the baby. She knows where I live—the little town I come from. It is a horrible feeling because everyone from this town who comes to give birth knows what happened, and that marks you for the rest of your life (Halperin et al., 2011, p. 391).

The interview format commonly used in research focusing on low morale among midwives has helped to “bring to life” the real issues that midwives face in their day-to-day life and what stressors they bring into the room when caring for a patient. One study offers this anecdote: “Everyone’s depressive really. People don’t want to come to work and take days sick. The more apathetic everyone gets, the worse it is going to get. Just when you think morale can’t get worse it does. Everyone is talking about leaving” (Hughes, Deery, & Lovatt, 2002, p. 49).

At least some of the disrespect shown to women in facility-based maternity care is taught to providers through modeling of negative behavior and as part of the formal training they receive. d’Oliveira et al (2002) offer this example:

At the medical school . . . we went to attend a delivery, a woman resident was doing it. She was sitting there in front and yelling at the mother: “Shut your mouth! Stop yelling and push! You knew what you were doing when you had sex, and now you see the result you’re going to cry? Try to push and yell quietly.” And we students stared and said to ourselves: “Wow, she’s really totally in control of the situation. She’s my idol!” (Brazilian doctor) (p. 1681).

In the same article, the author writes, “in some situations the use of disciplinary measures against patients has been legitimised. These measures are often developed within a system as being the correct way to deal with various problems, and generations

of professionals learn these techniques during training or when they work in a particular environment” ( d’Oliveira et al., 2002, p. 1683).

A study of nurses and midwives in South Africa similarly found that abuse was so prevalent that it was considered a professional norm and necessity in the childbearing setting. The author concluded that

. . .the clearest indication though was visible [of the normalization of violence] in one of the meetings held to discuss the study reports when a senior nurse asserted that she did not think that there was a midwife in the service who had never slapped a patient in labour. She continued to assert that it was a misrepresentation to describe this as “beating” (the patients’ word) as, she explained, one would “cup one’s hand and slap the thigh” and she proceeded to demonstrate this with gestures” (Jewkes, Abrahams, & Mvo, 1998, p. 1790).

### **Measuring the prevalence of D&A**

There is a range of how patient satisfaction levels are estimated from online or mailed surveys in a defined post service time period, to focus groups in the informal setting, or individual interviews with women, family, and community members. The 2013 survey of measures of satisfaction by Sawyer et al. reviews the various quantitative tools that have been validated in order to assess patient perceptions of care they have received in the maternity setting. These include the ones most commonly employed in the US domestic setting such as the 38 item Labor and Delivery Satisfaction Index (LADSI), the Patient Perception Score (PPS), the Mackey Childbirth Satisfaction Rating Scale (MCSRS) and the intrapartum-specific Patient Perception Questionnaire (QPP-I) (Sawyer et al., 2013). While these tools show good construct validity and have high reliability, they are generally used as tools for marketing purposes, whereas qualitative tools offer insight into whether a researcher’s and staff’s ideas of what “counts” as D&A and what women perceive to be D&A match. However, since no current health information

systems (HIS) capture any data on D&A or RMC, these tools remain necessary in trying to decipher the scope of the problem and potential solutions (Rosen et al., 2015).

Despite the variation in how data are collected, there is global consensus that so many women experience some form of humiliation, disrespect, condescension, or abuse by health workers during childbirth, that such behaviors are often considered the norm by communities (Abuya, Warren, et al., 2015; Asefa & Bekele, 2015). Abuya et al. (2015) found that, in a sample of Kenyan women, 1 in 5 reported any form of D&A. Asefa and Bekele (2015), found similar numbers in Ethiopia with 22% of participants in a sample of 173 reporting having experienced D&A. In the industrialized world, patient reports of abuse in the healthcare setting fared about the same. For example, a qualitative study of postnatal women in Denmark found that up to 28% of participants subjectively reported having experienced abuse by a health worker (Schroll, Kjærgaard, & Midtgaard, 2013). Another study found that in a sample of 160 women who had a planned homebirth in the US, over 23% of them cited a previous negative hospital experience as a reason they chose to stay home to give birth (Boucher, Bennett, McFarlin, & Freeze, 2008). Other researchers found much higher rates; a study in Nigeria found that of 437 participants, 98% reported some type of D&A on a questionnaire given to postpartum women (Okafor, Ugwu, & Obi, 2015). This discrepancy points to the fact that D&A does not have a standardized definition for researchers to use. Also, while D&A is clearly a prevalent issue, some observational studies cite much higher rates of abuse than subjectively reported by women themselves. For example, in the same study that 22% of Ethiopian women reported D&A, researchers documented that 78.6% of the same women faced D&A based on the Universal Rights of Childbearing Women's 7 categories (Asefa &

Bekele, 2015). Aside from the variable definition of D&A, cultural factors such as women's willingness to speak up about D&A, limitations in their recognizing behavior as D&A rather than the norm, and a lack of knowledge on human rights issues can influence D&A reporting rates. Negative experiences also vary with environment, individuals, and in severity based on socio-economic, religion, age, parity, and regional nuances.

A study among Cambodian women found that "women who gave birth at facilities felt unsafe in the hospital and health centres due to poor midwifery care" (Ith, Dawson, & Homer, 2012, p. 3). The authors also note that women reported experiencing a large range of disrespectful and abusive care by providers they encountered at facilities. Among them were accounts of: yelling, insulting their cleanliness, rudeness, physical abuse, lack of privacy, confidentiality, absence of provider support in labor and refusal to allow women to bring a labor companion with them. A Brazilian study interviewed women about their experiences in hospital-based violence against women program and found that verbal abuse and intentional humiliation were common. One woman reported,

A nurse was attending to me, she told me I had to help, to push. At that moment I couldn't. I was yelling. The nurse gave me a slap. That made me very ashamed, she treated me as a bad girl (d'Oliveira et al., 2002, p. 1682).

In Iran, a study within three facilities found that almost no patients reported they were satisfied with the level of respect and dignity they felt by health workers during their maternity experience there (Ebrahimi, Torabizadeh, Mohammadi, & Valizadeh, 2012). In Tanzania, 112 women (and their male partners) who had delivered within the previous 14 months, community leaders, and health workers all participated in a study that used in-depth interviews and the Grounded Theory method to look at D&A perceptions and prevalence. At first, the women expressed that their experience was neutral; however,

further probing by the researcher resulted in their recounting things that objectively could be defined as abuse based on international human rights guidelines (McMahon et al., 2014). The authors identified a model for how negative behaviors toward women in labor resulted in low facility use, and a pathway from the normalization of abuse to low utilization of facilities in the community.

### **What is respect?**

Compassion in healthcare is more frequently addressed in end-of-life care literature than in the context of childbirth; it is obviously a defining concept in palliative care. However, as central as compassion is in palliative care, respect has also emerged as a key aspect of the care hospice workers provide. Most of the lessons learned can be replicated within the vulnerable time period of pregnancy and childbirth and, although compassion and respect may differ definition-wise within some linguistic, religious or philosophical sources, when applied to the maternity setting, they are practically synonymous. While professional bodies such as the American Nurses Association (ANA), the American Association of Colleges of Nursing (AACN) and the American College of Nurse-Midwives (ACNM) acknowledge that respect and compassion are key features of both nursing and midwifery, they do not have a clear definition of the concepts within the literature of these disciplines (ACNM, 2013; Milton, 2003; Ulrich, Breugger, & Lefton, 2009). Maternity care is a combination of nursing, midwifery, philosophy, ethics, public health, and several other social sciences. Therefore, the inclusion of these disciplines in a search for what respect means in the healthcare setting is critical. Because the concepts of respect and compassion are heavily influenced by environmental, cultural, ethical, and socio-economic factors, the definitions are abstract

and will always be variable between individuals. Respect and compassion are also often overlooked in concept analyses since they have relevance in everyday life, so most people feel they are already familiar with them. However, the concepts are hard to define since they are largely entities tied to individual perceptions, which clearly vary and are influenced by personal experience, cultural, educational, religious, political, and economic factors.

Ulrich et al. (2009) explains, “People talk about respect in the way we used to talk about quality - seeming to believe you know it when you see it but have a difficult time articulating what it really means conceptually and behaviorally” (p. 6). DeLellis (2000) points out that, “There are no true synonyms for respect [but] there are numerous words that are often associated with respect” (p. 4). Prominent associated concepts in the literature on philosophy, leadership, linguistics, and health disciplines are appreciation, reverence, honor, humanism, and compassion (Browne, 1993; DeLellis, 2000; Dillon, 2010). However, when people behave in a manner reflective of these concepts, it is without the expectation that they do so; rather it is merely a preferential behavior that they choose. Respect on the other hand holds stronger ethical connotations and is considered by most authors to be obligation. Many social scientists use it as a central theme in research pertaining to human morality (Beach, Duggan, Cassel, & Geller, 2007). Despite its definition remaining somewhat elusive, several ideas and theories are based on its presence or absence. Respect is also unique in that it is both an action (a behavior) as well as an attitude. It stands to reason that when someone behaves respectfully, they obviously also will probably embody the attitude of respect, yet both instances have features distinct from one another.

Formal ideas about what constitutes respect are deeply rooted in the discipline of philosophy. The most frequently cited example is seen in the moral philosophy of Immanuel Kant. His primary thesis is that all people deserve respect purely because they are free rational beings (Dillon, 2010). In his definition, respect is “the acknowledgment in attitude and conduct of the dignity of persons as ends in themselves” (Dillon, 2010, section 2.2). In determining that all people are dignified and deserving of respect, the act of disrespecting a person is deemed morally wrong. Kant also stated that, “Respect is always directed only to persons, never to things...” (DeLellis, 2000, p. 2). Modern philosophers dispute this point and have developed several theories to distinguish various forms of respect to illustrate this. One example is how Hudson (1980) divided respect into four categories: (a) evaluative respect; (b) directive respect; (c) institutional respect; and (d) obstacle respect. Evaluative respect is the type Kant classified - that between two people. Directive respect refers to an action based on guidance, such as respecting a speed limit. Institutional respect could take the form of saluting your nation’s flag or standing when a judge enters a courtroom. Finally, obstacle respect is the type a scuba diver might have for ocean predators such as sharks.

Feinberg (1975) identifies three classes of respect based on the attitude of the giver (*subject*) of respect: (a) uneasy and watchful (such as a firefighter in a burning building); (b) regarding the object as making a rightful claim on our conduct (the kind of respect Kant says all people are deserving of); and (c) reverence (being humbled by the birth of a baby) (p. 1). Dillon (2010) observes that, “Feinberg sees different forms of power as underlying the three kinds of respect; in each case, respect is the acknowledgment of the power of something other than ourselves to demand, command,

or make claims on our attention, consideration, and deference” (Feinberg, 1975, section 1.2). Dillon (2010) adds the idea that respect is both an attitude and a behavior, which is the component most relevant in nursing and midwifery - that of “care respect”, that is the form of respect when the object has a unique value and so it is respected out of benevolence.

One of the earliest and most referenced definitions of compassion/respect comes from Buddhism and relates to understanding the suffering of others and generating a means to help alleviate it. Buddhists seek to acknowledge and relieve suffering of all beings and so compassion forms one of the central values (“Buddhist Studies for Secondary Students, Unit 6: The Four Immeasurables. Retrieved from ‘BuddhaNet’ at,” n.d.). Much like the Latin origins of the word for compassion, they acknowledge that in order to be compassionate to others (the behavior), one must recognize their own suffering (‘to bear or to suffer’) and first be compassionate towards oneself (the attitude). Therefore, practicing compassion not only improves one who is cared for but also for the person who is providing care. According to Schmidt (2004), compassion is comprised of the seven tenets of the Buddhist notion of “mindfulness” (p. S-9). They are (a) Non judging, (b) Acceptance, (c) Nonattachment, (d) Beginner’s mind (seeing things as if for the first time), (e) Nonstriving, (f) Gentleness, and (g) Kindness.

Schmidt (2004) also states that, “The inner relationship is the basic template for any encounter with the world” (Schmidt, 2004, p, S-8). This reinforces the idea that compassion comes from within and like respect, is both an action (behavior) and an attitude. It, therefore, is also somewhat reflexive in that both the person behaving



compassionately and the recipient of the compassion (e.g., the patient) are affected simultaneously.

Compassion appears in the doctrines of all major world religions, not just Buddhism. Judaism similarly teaches about compassion; for example, 1st century Rabbi Hillel explained, "That which is hateful to thee, do not do unto your fellow man. That is the whole Torah. The rest is mere commentary" (Hillel, n.d.). The ultimate model of compassion in Judaism is that of how God treats man, and emulating this is the overarching theme of the religion. Elements of the values that Jews believe encompass humanity include kindness, doing charitable and good deeds, and respecting others (Rich, 2014). Reflected in the laws of keeping the Sabbath where the Torah prohibits work, exception is made to heal the sick, which is a direct result of compassion as a central belief.

Islam similarly advocates for the belief that God is the ultimate model for compassion. In fact, God is referred to as Rahman, or Compassionate, in Muslim daily prayers, making it a primary concept studied in Islam (Engineer, 2001). Muslims believe that compassion requires being sensitive to others suffering, much like Buddhism. The Q'ran also states that Muslims should be merciful and compassionate to each other. The belief is that only God (Allah) can show this behavior towards all things, whereas humans are limited in their worldly views. However, humans should try and emulate Allah as much as possible and be compassionate and merciful to everyone as equally as possibly even if they are not a practicing Muslim.

In Hinduism, there are ten 'yamas' or restraints that should be followed. The seventh is called Daya, which translates from Sanskrit to mean compassion (Davis,

2010). Daya means, “conquering callous, cruel and insensitive feelings toward all beings...Foster sympathy for others’ needs and suffering. Honor and assist those who are weak, impoverished, aged or in pain” (Das, n.d.). Like the other major religions, Hindus also believe that compassion is synonymous with having the qualities of God and should be emulated as best as is humanly possible; this is called Ahimsa and is what Gandhi based his nonviolent theories on (Gandhi, 1958). Ahimsa refers to serving others with an open heart through direct actions.

Finally, Christianity advocates that God, through Jesus, embodies compassion. Christians believe that God has experienced suffering through the human body of Jesus and, therefore, can understand the human condition; in this way it is empathetic. In the New Testament, it is written, "But when he saw the multitudes, he was moved with compassion on them, because they fainted, and were scattered abroad, as sheep having no shepherd" (King James Version, 2000, Matthew 9:36). The Christian Bible advocates for followers to act compassionately towards others, even when this means giving up personal desires or inclinations. This is reflected in the frequently quoted, “Love thine enemies” implying that Jesus intended his followers to place compassion as the paramount value above all others, much like Gandhi.

### **Defining Respect and Compassion Within the Nursing and Midwifery Professions**

The linguistic, religious, and philosophical observations and definitions about compassion and respect appear to be aligned with professional healthcare organizations. However, much of this has been somehow lost within nursing, midwifery and medical education in the modern era. Health workers often distance themselves intentionally from patients and are careful not to share personal experiences, particularly within the

childbearing process. That is because within the current western model (which most educational models in healthcare are based on), health workers are typically encouraged to separate themselves as individuals from their professional role and instead present themselves as part of the field or cadre that defines them. In some cases, it may even be considered unprofessional to share his/her personality or opinions with a patient in the medical context and act as equals on a personal level.

Defining respect and compassion within the maternity setting will hopefully shift this paradigm as it not only has the potential to improve patient outcomes but also job satisfaction among health workers. Nurses and midwives find more self-efficacy in their work as they incorporate aspects of respect and compassion by shifting to more positive attitudes and pro-social behaviors (McCullough, Kilpatrick, Emmons, & Larson, 2001). This will create a circular model of compassion through a more equalized relationship between patient and provider with both parties benefitting. Grant and Gino (2010) found that, “When helpers are thanked for their efforts, they experience stronger feelings of self-efficacy and social worth, which motivate them to engage in pro-social behavior” (p. 946).

Since respect and compassion are a combination of beliefs and the actions that reflect them, several methods of measuring their presence within the maternity setting have been used. Qualitative methods assess perceptions of both the subject and object of respect (or disrespect) and compassion; while quantitative methods measure benchmarks for things like humanized or woman-centered care; most often, patient satisfaction surveys and utilization rates are the primary design feature. Several studies use patient satisfaction instruments that incorporate focus groups, interviews or surveys (Mollart et

al., 2013; Vahey et al., 2004). Others utilize human rights “audit” techniques or intense content analysis of informal or semi-structured interviews. One quantitative method that has been used is test-retest for interventional programs such as staff humility training or the introduction of woman-centered care. Humility training, or methods to introduce humanized care within health systems, are relevant in the concept clarification of respect. Browne (1993) explains that, “Many of the conditions necessary for humanized care are actually instances of respect. These include perceiving patients as unique, autonomous, irreplaceable, whole persons with inherent worthiness” (Browne, 1993, p. 213).

Another method of assessing respect and compassion is by observing interactions and then looking for common themes that emerge and systematically examining them for values that fit the broad definitions of these concepts. In 1997, Browne did a thorough examination of respect as a concept within healthcare. She defined three indicators of respect: (a) nonverbal messages that convey respect; (b) verbal messages including tone of voice, honesty, and interest; and (c) nursing actions aimed at protecting patients’ sense of privacy and modesty, explaining procedures, and allowing them to make their own choices (Browne, 1997). Then, when observing behavior, she applied these categories of actions to find themes that emerged from the field research on respect. These were: active listening, trying to understand patient perspectives, behaving sincerely, allowing patients autonomy in decision-making about their care, exhibiting patience and protecting patient dignity (Browne, 1997).

A quantitative tool for measuring compassion (and empathy) is the Interpersonal Reactivity Index (IRI). The IRI measures perspective taking, empathic concern, personal distress, and fantasy, which all relate to compassion conceptually. Research conducted by

Davis (1983), employed a multidimensional approach using the IRI in relation to social competence, self-esteem, emotionality, sensitivity to others, and intelligence. It is critically important to observe and record compassion and respect between providers and patients as a means to improve health outcomes and health systems. Roshi Joan Halifax (2012), developed the GRACE model to train health workers in compassion based on Buddhist principals. GRACE consists of 5 steps: (a) Gathering attention, (b) Recalling intention, (c) Attuning to self and other, (d) Considering what will serve, (e) Engaging, enacting, and ending. Halifax advocates this model because, “We live in a time when science is validating what humans have known throughout the ages: that **compassion is not a luxury**; it is a necessity for our well-being, resilience, and survival” (Halifax, 2012, last paragraph). This is a meaningful, important, and literal statement when applied to the context of maternity care, D&A and respect by health workers.

### **The Three-Delay Model**

The “Three-Delay” model as related to maternal mortality was first published in 1994 by Thaddeus and Maine and is based on the principle that most maternal deaths are preventable because, “if prompt, adequate treatment is provided, the outcome will usually be satisfactory; therefore, the outcome is most adversely affected by delayed treatment” (Thaddeus & Maine, 1994, p. 1091). The Three-Delay method of categorization is very helpful in understanding D&A because a clear line is drawn to show the consequences that negative care can have on women’s future health-seeking behaviors. Conversely, respectful care emerges as a clear solution when approaching maternity care from a Three-Delay Model perspective. This model was also selected as a means to evaluate the literature because its design is recognized as a standard taxonomy in global maternal

health research and most study designs and service delivery interventions are based on the concepts presented within the model. Explained most simply, the three delays are:

*1. The Delay in Deciding to Seek Care at A Facility*

Factors that contribute to the decision-making for the individual, her family or her birth attendants include the general status of women in her cultural context (i.e., whether she is “worth” getting treatment for), the distance from the facility, the ability to recognize an obstetric complication, economic considerations, perceived quality of care at facilities, and previous experience with facility-based care or perception of care provided there.

*2) The Delay in Reaching Care*

The key factors in this delay have to do with transportation issues such as road conditions, and the cost or availability of a means to transport.

*3) The Delay in Receiving Adequate Care Once at the Facility*

Factors for this delay include the availability of equipment, supplies, appropriate staffing, quality of care, and adequacy of a referral system when transport to a facility with a larger scope is required (Thaddeus & Maine, 1994, p. 1092).

The development of the Three-Delay Model has helped to begin a transition within maternal outcome research from exclusively a medical approach that looked at the key five obstetric complications that cause maternal death to one that now begins to include cultural, economic, social, and psychological factors which also ultimately contribute to the development of medical complications. One meta-analysis focusing on maternal mortality statistics explains that research on this content is essentially all biomedical based and entirely ignores political and cultural factors (Gil-Gonzalez,

Carrasco-Portino, & Ruiz, 2006). However, these factors often guide the decision to utilize facility-based care by individuals and communities so their presence is critical in determining pregnancy outcomes (Kujawski et al., 2015). It should be noted that one limitation of the Three-Delay Model is that it only pertains to intrapartum (labor and delivery) acute complications and has not been evaluated and validated in terms of outpatient and preventative services such as family planning or antenatal care that may prevent or provide early identification of potentially dangerous intrapartum incidents. This is because it is designed to look at barriers in an acute situation where decision-making must be made within a relatively short time period.

Consistent across the literature is the concept that maternal death due to a lack of skilled care is almost never the result of just one delay (Essendi, Mills, & Fotso, 2010; Thaddeus & Maine, 1994). However, there is evidence that the first delay (the delay in deciding to seek care) is the most prevalent (Mohammed, Elnour, Mohammed, Ahmed, & Abdelfattah, 2011). Certainly, for the purposes of this body of work, the first delay is the most pertinent as most consequences of D&A fall into this realm. First delays can be difficult to identify because they are often multifactorial (Pacagnella, Cecatti, Osis, & Souza, 2012). This is likely because the first delay is where key individual, cultural, financial, gender stratification, prior experience or perceptions of healthcare and educational factors come into play. This is of particular interest because changing peoples' perceptions, behaviors, and attitudes is more difficult to initiate than improving less variable concepts such as the need to improve knowledge levels (Pacagnella et al., 2012). Additionally, conversations about reducing second and third delay barriers become less germane without a primary look at first delay causes, since improvements in

transportation and service delivery are only relevant if women choose to utilize such services at all.

A large portion of global first delay literature discusses the minimal ability of individuals and traditional birth attendants (TBAs) to recognize obstetric complications and emergencies so a considerable portion of resources has been invested in educational and training interventions to improve their knowledge with varying levels of success (Alvarez, J L Gil, Hernandez, & Gil, 2009; Prata, Passano, Sreenivas, & Gerdtts, 2010). However, because these interventions have little to do with actual perceptions and attitudes, they remain secondary to this literature review. The focus here will be on the factors that affect decision-making in terms of why women may or may not seek out facility-based skilled birth attendants when they are readily available and accessible; most literature refers to this as ‘utilization’ studies, and they are closely linked with patient satisfaction research. There are obviously many other reasons why women delay or avoid seeking care, but the key to this literature review is to look at women who otherwise have access to health services but choose not to use them.

### **Vulnerability Theory**

The term “vulnerability” often connotes an image of victimhood and pregnant women are often lumped into this category as a segment of the population that carries increased inherent risk. However, for the purposes of deconstructing the root causes and ultimate consequences of D&A, it was used in this literature review as a lens through which to examine the social construct of healthcare systems and societal norms which have failed pregnant women, leading to them making unfavorable health-seeking decisions. As an example of this concept, in his study of HIV patients and vulnerability



theory, De Santis (2008) notes, “vulnerability can be defined in terms of experiences that create stress and anxiety and affect the physiological, psychological, and social functioning of a client” (De Santis, 2008, p. 275). Vulnerability theory essentially seeks to explain *susceptibility* to existing conditions; for example, similar situations can have dramatically different effects on individuals and populations, but the conditions are the root cause, not a function of, individual weakness. While one person might be able to overlook negative treatment by health workers, another might not be able to because of their level of susceptibility because of environmental factors. Within academia, vulnerability falls within the purview of preventing exploitation for the purposes of consent. This loosely encompasses the concepts of disrespect and injustice which are essentially also functions of susceptibility (Hurst, 2008). These are influenced by culture, economy, policy, and gender roles, which do not necessarily have roots in the health system itself, but in society at large.

Zakour and Gillespie (2013) hypothesize that social systems are to blame for these varying degrees of susceptibility in individuals and societies. They argue that in social work, for example, vulnerability is seen as a response to social and distributive justice (Zakour & Gillespie, 2013). Wisner et al. (2004) describe vulnerability as,

. . . the characteristics of a person or group and their situation that influence their capacity to anticipate, cope with, resist and recover from the impact of a natural hazard (an extreme natural event or process). It involves a combination of factors that determine the degree to which someone’s life, livelihood, property and other assets are put at risk by a discrete and identifiable event (or series or ‘cascade’ of such events) in nature and in society (p. 11).

This social approach to the concept of vulnerability falls outside the usual definition of Vulnerability Theory known within the nursing profession. Whereas nursing tends to lean on attributes of the individual’s health characteristics - physiology, genetics, and response

to pathology - the type of vulnerability relevant to global maternal health outcomes is of a broader social and political nature. Tomm-Bonde (2012) posits this same idea when she says,

What is too often ignored, and therefore absent, in much of the nursing literature is an examination of how gender, racialization, class and history intersect to shape socio-political-economic realities and, therefore, health. The nursing literature, particularly in North America, is constrained, failing to examine the political and ideological underpinnings of vulnerability. In its current state, the concept of vulnerability is a rigid, static concept, which does not inform the nursing paradigm in a substantive manner, nor does it foster comprehensive images and understandings of vulnerability (par 8 ).

### **Conclusion**

Data show that respectful maternity care (RMC) and its opposite, disrespect and abuse (D&A), occur within the maternal health care delivery in many (if not, most) regions in the world with consistency. Some of the root causes of D&A have been identified and described in recent literature. These include stress and burnout of health workers, poor working conditions, social inequality and gender role issues, and training programs that perpetuate maltreatment of women in childbirth. Literature also suggests a link between how respectfully women are treated with future decision-making regarding where and with whom they seek care in subsequent pregnancies. Since these choices can determine life-altering outcomes, it is critical to look at ways to guarantee that women are treated well enough to opt for care in the safest setting available to them. The first step in doing this is to determine a standardized definition of what respect means to women; only then can interventions be designed that can operationalize how to teach this to health workers and integrate this into service delivery. A definition that is 'one size fits all' can be a challenge to develop considering the individualistic component that respect requires to interpret individually based on things like life experience, culture, and spirituality.

However, a certain set of minimum standards should be possible considering the common threads within definitions for both respect in general, and for RMC that have been examined over time, and in all reaches of the globe through health research, religion, and philosophy. It is the researcher's hope that this study project will contribute to this end goal and address a gap in the existing literature about respectful maternity care.

Specifically, there is a lack of consensus about what constitutes "respectful" maternity care. Therefore, in order to address this gap, the following were the questions to be addressed in this research project:

- 1) What do women who have recently given birth consider to be respectful care by maternity workers?
- 2) What were their experiences of respectful care during childbirth and the immediate postpartum period?
- 3) How important is this to them in terms of their health-seeking behaviors?

### **CHAPTER 3. METHODOLOGY**

This chapter will provide an in-depth description of the research methodology that will be used to address the research questions. Since the research questions asked were inherently subjective in nature, a qualitative descriptive design using content analysis was implemented. Content analysis was selected as being most appropriate for this study because it is exploratory and there is a need to describe the themes that emerge from participant experiences and perceptions before subsequent studies can be designed to effectively produce any type of theory.

#### **Purpose**

The main purposes of this study were to explore what women who have recently given birth consider respectful care by maternity workers to be; what their experiences of respectful care were during intrapartum and the immediate postpartum period and how important this is to them in terms of their ongoing health-seeking behaviors. Ultimately, the research questions are rooted in the broader context of maternal mortality and morbidity globally. More specifically, literature indicates that an overarching theme in facility-based maternity care is a high prevalence of disrespect and abuse (D&A) by health workers during a time when women are most vulnerable. While D&A are somewhat subjective, attempts have been made to refine a set of behaviors deemed unacceptable in order to measure prevalence. As a result, D&A is now acknowledged as a key factor in why women intentionally delay or avoid health services that have been shown to improve maternal outcomes. However, the gap lies in that little has been done to work towards eliminating the negative behaviors by health workers that women experience in facility-based childbirth. This study aims to explore and standardize what

"respect" means in order to begin to create universal standards to replace D&A within the care of childbearing women with Respectful Maternity Care (RMC). Santa Cruz County serves as a valid initial exploratory study site due to the ethnic and cultural diversity, availability of a wide variety of health services, and the active alternative birthing community who have regular discourse about D&A within the health system.

### **Research Questions**

The research questions this study addressed were:

1. What do women who have recently given birth consider to be respectful care by maternity workers?
2. What were the experiences of respectful care of women who have recently given birth?
3. What are women's thoughts about the importance of experiencing respectful care in their future decision-making about seeking and accessing maternity services?

### **Qualitative Research**

Understanding other peoples' perceptions is paramount in the human experience because all relationships depend upon being able to anticipate the attitudes and behaviors of those with whom we interact. The complexities of this are born from a myriad of cultural, economic, political, and religious systems as well as individual lived experiences. Never more so is this the case as within healthcare where those seeking services are often at their most vulnerable and those delivering care are in the position to have a profound effect on the lives of those for whom they provide care. Maternity care is particularly delicate because the outcomes and the experiences a woman has giving birth ultimately can have a lifelong impact on entire communities.

While much of health research is quantitative and looks at outcome measures such

as mortality, morbidity, and efficacy, maternity care needs to be looked at through the eyes of the woman and her family. Qualitative research allows the opportunity to see into the minds of other people and learn clues about how they feel and what they think, which ultimately needs to be reflected in health policy and service delivery in order to truly improve lives. While quantitative research is often easier to manage within healthcare because it can give finite answers yielded from vast swaths of data, it rarely gives a full picture when used as a standalone. Qualitative research, while much more abstract, will eventually tell us how the individual perceptions influence outcomes more accurately. For example, a randomized controlled trial of a new drug can quantitatively tell us whether it is chemically more capable of eradicating disease symptoms than an older drug. However, it will not tell us whether people will be willing or able to use the drug as directed in order to get more benefits over the older drug. Qualitative research can describe otherwise intangible barriers, beliefs, attitudes, and ultimately behaviors; it is the only way to explore the human experience through complex narratives.

Krippendorff (2004) explains that the word ‘research’ is reflective of “a repeated search within data for apparent patterns” (p. 81). Qualitative research seeks to do this by finding answers to research questions using well-defined processes of data collection, organization, and extrapolation in order to produce findings that are not predetermined (Creswell, 2013). While quantitative research is structured, rigid, and based on statistical assumptions, qualitative research is exploratory and iterative. That is, interview questions can be rephrased or guided based on participant responses or adjusted according to what is learned as the research process unfolds. Qualitative research is based primarily on textual data (transcribed interviews or field journals, for example) and, therefore,

descriptive in nature as it pulls together information from multiple sources. Denzin & Lincoln (2011) describe qualitative researchers as a bricoleur and quilt-maker producing results that are “ a pieced-together set of representations that are fitted to the specifics of a complex situations” (pg. 4).

### **Content Analysis**

Content Analysis is interpretive and requires close reading of a relatively small amount of textual data, the interpretation of these data into narratives, and then performing analysis within the context of social and cultural confines where the research takes place, since it is context sensitive (Krippendorff, 2004). Since texts (or in the case of this study, transcribed interviews) always contain multiple meanings, it is important to approach them knowing that context is particularly influential in interpreting data and a critical part of addressing trustworthiness (Graneheim & Lundman, 2004). While there are several types of content analysis, this study used the most conventional methodology whereby categories and themes were derived directly from the text because it is most appropriate in describing phenomena such as emotional reactions (Hsieh & Shannon, 2005). While Grounded Theory and Phenomenology are similar to this form of content analysis, the former methods lead to the development of theories where the latter is limited in that it primarily assists with overarching concept developments through a descriptive process. In fact, many qualitative methods share similar features in that they allow researchers to immerse themselves in the data, use open-ended interviews, and create thematic categories (Hsieh, Hsiuh-Feng & Shannon, 2005). This study employed these techniques with an eye towards replicability and removing the personal authority of the researcher, since the aim was to continue posing the research question in a variety of

contexts in order to ultimately draw similarities (and differences) out and define a universally applicable concept of respect in maternity care. Of the many uses of content analysis, the three most pertinent to this study were: (a) to construct and apply communication standards; (b) to reflect attitudes, interests, and values (cultural patterns) of population groups; and (c) to describe attitudinal and behavioral responses to communications (Berelson, 1952). Content analysis was effective for these purposes because it uses a process of feedback loops that systematically puts material into categories that are continuously revised and refined using triangulation as a means to create reliability (Mayring, 2000). Specifically, this study used the process described by Krippendorff (2004): (a) Unitizing, (b) Sampling, (c) Coding, (d) Reducing, (e) Inferring, and (f) Narrating.

### **Unitizing**

Units are used to break data into bite-sized pieces in order to make analysis systematic. For the purposes of a qualitative study looking at human perceptions through semi-structured interviews, the most obvious unit to use will be codes that emerge from participant responses. These codes might consist of a single word; for example, when asked why participants think a nurse was impatient with them, the word ‘busy’ recurred in interviews. Some themes also consisted of an entire phrase. Essentially, the coding units sought to capture an idea, emotion, or belief that addressed the research questions and could be used to create clusters or categories within which several codes could be grouped. This led to the identification of broader themes that were used to answer the research questions within the correct context.



## **Sampling**

**Inclusion/exclusion criteria.** Research participants came from a purposeful sampling of women in Santa Cruz County, a somewhat rural region of Northern California, who had given birth in the past 6 months in a variety of settings. Sutter Maternity Hospital and Surgery Center in Santa Cruz offers several support groups for new parents that are well attended, even by women who did not receive health services through the Sutter Maternity Center itself. The support groups are free to all community members and focus on various aspects of the postpartum period from birth to 1 year. The support groups are split into two sections, each of which are led by a Board Certified Lactation Consultant and/or Registered Nurse. The groups are advertised as "New Parents Support Group" with one of them for parents with babies aged 3 weeks to 4 months, and the other for parents with babies that are aged 4-12 months.

The investigator recruited women for the study at the beginning of several support group sessions, explaining the study and giving contact information so that potential participants could express interest. Semi-structured interviews lasted under an hour and continued with participants until saturation was reached during data analysis. In qualitative content analysis, there is no rule as to how many participants need to be included in the study; however, in other qualitative methodologies, this number is typically between 5-30 (Creswell, 2013).

The inclusion criteria included: (a) women who live in and received all of their prenatal and intrapartum care in Santa Cruz County, California; (b) gave birth in the previous 6 months; (c) were first-time mothers; (d) were fluent in English; and (e) agreed to participate in the study. Exclusion criteria included: (a) anyone for whom the

researcher provided any care for during the pregnancy, labor and delivery, or postpartum period; (b) women who did not receive all prenatal care within and give birth in Santa Cruz County; (c) women who gave birth more than 6 months prior to study recruitment; (d) women who were not proficient in reading and speaking English; and (e) women who had a fetal or neonatal death occur or those who had given birth to an infant with a life threatening condition.

The reason for choosing a wide time frame for women to be eligible to enroll in the study was to address various angles of the research questions. For example, the more recent postpartum participants had a more detailed recall of their experiences of giving birth. Also, the less recent postpartum participants were more likely to be considering subsequent pregnancies and how they will choose where to seek maternity care.

**Setting** Santa Cruz County offers diversity in age, ethnicity, economic status, and educational levels drawn from a population of 262,382 residents (US Census Bureau: Santa Cruz County, 2010). The most recent report from the Santa Cruz County Health Services Agency summarizes birth statistics from 2014 that were extrapolated from birth certificates filed in the county. Most notably, there were 3,069 live births, 53% of which were covered by MediCal insurance (low income state coverage). Additionally, 21% of live births were to women over 25 years of age who did not have a high school diploma. A majority (82%) of women obtained prenatal care during the first trimester, with 18% receiving care in the 2<sup>nd</sup> or 3<sup>rd</sup> trimester (0.4% had no prenatal care at delivery). For more specific age, ethnicity and mode of delivery information see Tables 2 through 6.

Additionally, Santa Cruz County is known for its generally liberal atmosphere, inclusiveness, and acceptance of alternative thinking that extends into politics, wellness,

and spirituality. Women seek maternity care in a variety of places in Santa Cruz, all of which are frequently discussed on social media, at community events, and in local news. Births may take place at any of the following places and be attended by a variety of birth attendants:

- Dignity Health System's Dominican Hospital: a Catholic tertiary care center with births attended by Certified Nurse-Midwives (CNMs), Family Practice Physicians, and Obstetrician/Gynecologists (OB/GYNs).
- Sutter Maternity and Surgical Center: A Baby-Friendly Facility serving low risk women in a birth center-like environment with births attended by CNMs, Family Practice Physicians, and OB/GYNs.
- Watsonville Community Hospital: serves primarily Latino population in the southern part of the county with births attended by OB/GYNs.
- Full Moon Birth and Family Wellness Center: a new freestanding birth center operated by Certified Professional Midwives (CPMs), which opened in 2018
- Homebirths attended by CNMs, CPMs, direct-entry midwives (although this group of midwives is not legal in California), or are unassisted births

**Interview setting.** Participants were given the option of completing the interviews either in a private conference room at Sutter Maternity and Surgery Center or another private location of their choosing (e.g., their homes) The participants had the option of having their baby present for the interview, but otherwise the only other person present during the interview will be the researcher.

### **Coding, Reducing, and Inferring**

Because inductive category development was used, criteria were formulated from theoretical background and information found within the literature review (Mayring, 2000). Coding was the most critical step in developing these categories and is the core feature of content analysis; therefore, codes were created so that ultimately, no data was excluded due to lack of suitable category, nor did it fit into more than one category

(Graneheim & Lundman, 2004). Specifically, codes were created using the approach explained by Hsieh and Shannon (2005):

- 1) Read all interview transcripts word for word by first highlighting key words that capture main concepts
- 2) Approach the text by making notes of first impressions
- 3) Create labels for codes that are reflective of all the various key thoughts
- 4) Sort the codes based on how related or linked they are and make group codes or clusters (these will be arranged using a tree diagram)
- 5) Create definitions for each category and subcategory that is developed

To aid in this process, the most recent version of ATLAS.ti was used to assist in the organization of codes and to identify relationships between categories. The researcher developed inferences based on the observed similarities and differences between participant perceptions and predicted behavior of future health-seeking choices they will make based on past experiences.

### **Narrating**

Categories, themes, and their resulting inferences were transformed into a detailed narrative, which was as exhaustive as possible, in order to include all data collected during the interviews. This narrative was set within the context of the theoretical framework of Vulnerability Theory, in relation to the existing body of literature pertaining to D&A and RMC, the features unique to the study population in Santa Cruz County, and finally, with reflection, as to how these findings can be further explored within the context of the global maternal health setting.

## **Validity and Reliability**

Validity refers to the extent to which it is possible to show that the research questions asked are actually answered and that the inferences made reflect a causal/influential relationship with the data itself. Krippendorff (2004) reminds us that merely repeating a study does not validate inferences made based on the data collection, rather, this will only explain to what degree the original data collection was reliable. For this reason, addressing validity is difficult in qualitative research due to small sample size and the more abstract nature of the data and analysis used. Similarly, reliability is not a good concept for the purposes of qualitative research because the variable nature of the human experience makes replication almost impossible without modifications of study design to account for population, environment, culture and other influential factors.

## **Trustworthiness**

The establishment of trustworthiness of the data collection, analysis and interpretation is considered a measure of how qualitative researchers assure that: (a) transferability, (b) credibility, (c) dependability, and (d) confirmability are evident in their study. Lincoln & Guba (1985) clarify that these are the four best methods to establish trustworthiness.

Transferability is a means by which the researcher shows that the findings are applicable in contexts other than just where the research took place (Guba & Lincoln, 1985). This was particularly important in the proposed study since a main goal is to begin to define concepts and ideas that can result in a definition and concept of "respect" and, ultimately, be used to develop a universal model of respectful maternity care based on this concept. The primary means to assure transferability is to give in-depth detail about

the researcher, the study context, and participant demographics in order to allow the reader to decide to what degree the findings are applicable to other groups (i.e., generalizable) versus specific to only the defined study context. As much detail as is possible was provided in the final narrative in order to allow for a transparent evaluation of transferability.

Credibility is a method of internal consistency that asks the researcher how confident they are in the truth of the findings and inferences they make based on the context, research design, and participants. Credibility can be established through prolonged engagement with the community in which the study takes place, continual observation, peer debriefing and participant checks (Guba & Lincoln, 1985). In the case of this study, prolonged engagement was not possible, however, other approaches to build immediate rapport were employed. For example, interviews took place in a private place chosen by the participants with no observers, the researcher disclosed all personal connections to local maternity care services, and the participants were informed that they can drop out of the study at any time. Continual observation was used as the researcher routinely reviewed social media for local conversations pertaining to the research question and personal observations made while working as a clinician in the maternity setting were recorded. Peer debriefings took the form of having the academic advisor, who is experienced in this research methodology, independently review a sampling of interview transcripts to develop codes, categories (clusters) and themes and were then compared to the researcher's. When differences were found, the academic advisor and researcher discussed these and came to a consensus, and revision of codes, categories and themes were made as indicated. Finally, member checks were done whereby participants

were in agreement with the researcher's interpretation of the data they provided and were asked if they could offer reasons for the patterns that the researcher thought had emerged from the data collection.

Dependability asks whether repeating the study would yield consistent results. Similar to credibility, an external audit by the academic advisor was the best way to assure dependability. An external audit allowed for the researcher's findings and inferences to be questioned, to identify gaps and to refine the iterative process. For this reason, the process of checking dependability was ongoing throughout the data collection and analysis phase rather than just cumulatively.

Confirmability assumes that the researcher is not objective. This was a possible challenge to this study as the researcher is a women, mother, and maternity health care worker and, therefore, could unintentionally infuse predisposed ideas, beliefs, and biases into the data rather than relying solely on participants' input. The best way to curtail this was thorough a description of how the researcher ultimately made decisions about how categories were created, which themes carried the most weight, and how decisions within the iterative process were made during the final narrative (Shenton, 2004). The documentation of this process was through the researcher's composition of memos that described the processes used to code, analyze and conduct member checking of the data. This established an audit trail that documented the process for future reference.

### **Interview Guide**

The interview guide (see Appendix A) addressed the central questions of the study and provided an outline, including follow up questions (i.e., probes) for the direction that the semi-structured interviews followed. Specifically, questions probed the

issues surrounding:

1. What do women who have recently given birth consider to be respectful care by maternity workers?
2. What were the experiences of respectful care of women who have recently given birth?
3. What were the thoughts of women about the importance of respectful care in decision-making about seeking and accessing future maternity services?

### **Limitations**

Limitations of the study include the fact that human experiences are intertwined and to some degree, the process of childbearing is so embedded in physical, emotional, and social factors that experiences that occurred outside of the actual intrapartum interaction between health workers and participants may have influenced the event itself. For example, a woman who is defensive and suspicious of hospitals upon admission might elicit more negative responses from staff than one who is optimistic and subdued. Also, the acute and variable experience of childbirth can come into play; an emergency medical event in birthing or a woman's perception of pain while giving birth can easily change the dynamic. These situations are valid in the sense that respect in childbirth should inherently be universal; however, generalizing findings when specific obstetric cases or participants do not necessarily represent the norm should be acknowledged. Another limitation is that Santa Cruz County has its own specific local culture and style of maternity care that may have resulted in data that is only useful in addressing issues in the study population. The participants were recruited from a local New Parents Support Group, which only consisted of women that self-selected to attend the meetings. Finally, the researcher's personal and professional experiences had the potential to bias the interpretation of the data.



### **Human Subject Protection and Confidentiality**

Prior to recruitment or initiation of this study, the researcher obtained approval from the Committee on Human Studies (CHS) of the University of Hawai`i, Mānoa (UHM) as well as approval from Sutter Health Systems where there is an internal review board specially tasked with the protection of human subjects in research studies being conducted in any of their sites.

Confidentiality of women was maintained at all times. The researcher attended the New Parent groups and spent time before the group session explaining the study. Women attending the group were asked to contact the researcher if they had an interest in participating. Once potential participants contacted the researcher, eligibility to participate was confirmed. A time and place was chosen that was both convenient for the participant and provided privacy for the process of obtaining written informed consent and for the duration of the interview. Informed consent was obtained (see Appendix B) before the interview began and the participant was afforded time to ask questions or have anything about the study explained that she was concerned about.

Once consented, each participant was assigned a study identification number that was used for the duration of their involvement in the study. The interviews were recorded and then transcribed. A professional transcriptionist was used for this; participants were made aware of this fact as part of the consent process. The transcriptionist was asked to sign a confidentiality agreement, which included that all materials from the study were to be returned to the researcher and no copies of any of the research materials could be made at any time. All data collected as part of the study was kept on the researcher's

password-protected laptop in an encrypted file and was accessible only to the researcher. Signed written informed consents were stored in a locked filing cabinet separate from the data collected to further ensure confidentiality. All research materials were destroyed after the completion of the study per UHM CHS and Sutter's IRB requirements.

## **Chapter 4: RESULTS**

This chapter will present the results of this study and include descriptions of the participant sampling and the content analysis steps, specifically the open codes, code groups, and ultimately the themes that emerged from completing the analysis of the data.

### **Participants**

Recruitment was done at the New Parenting Groups at Sutter Maternity and Surgery Center (SMSC). The groups are open to anyone with a baby less than one year of age regardless of where they live, what insurance they have, or where they delivered their baby. There is no cost to attend the classes which are led by a staff member whom also is a lactation consultant at SMSC. A total of fourteen women volunteered, ten of whom met inclusion criteria to participate. Of the four who were excluded, one had a baby that was older than six months of age, two either lived or delivered their babies outside of Santa Cruz County, and one was under 18 years of age. The ten who met all inclusion criteria were consented and semi structured interviews were completed using the IRB approved research question guide. The age range and ethnic makeup of the group can be seen in Tables 5 and 6. Seven of the women had normal spontaneous vaginal deliveries, two had low transverse cesarean section, and one had a vacuum assisted vaginal delivery (Table 7).

### **Data Analysis Process**

Despite anticipating that the interviews would take an hour (or more), the actual range was from 15 to 32 minutes long. The interviews were recorded using an encrypted audio device as per regulation by SMSC IRB. The audio files were then sent using a

protected and encrypted server to Homerow Inc, a transcription services that has a confidentiality agreement with Sutter and is contracted to provide services for all research projects approved by their IRB. Transcripts were returned via official pathways behind the Sutter firewall to ensure the protection of all participants. All material was deidentified during this process. Transcripts were then uploaded to Atlas.ti® qualitative software to aid in the content analysis of the data.

The data analysis resulted in 233 level I open codes (see Appendix E). These open codes were then clustered into 11 categories (or code groups) (see Appendix E) which gave way to the creation of five themes that address the building blocks of what women perceive respect in the maternity setting to mean. These themes, which will be discussed in this chapter, are: *1) Needs Were Met In a Timely Manner; 2) Care is Patient Centered; 3) Overall Feelings of Kindness; and 4) Caregivers Are Experts; and 5) The Environment is Safe.*

### **Needs Are Met in a Timely Manner**

The building blocks of the theme "*Needs Were Met in a Timely Manner*" are derived from the categories "Attentiveness" and "The Staff Was Busy." Attentiveness typically was expressed in terms of how responsive maternity staff were when women needed something (support, advice, supplies, etc.) and how the staff's response made them feel. Women at times felt they needed to ask for things more than once, were left waiting for long periods, or even felt hesitant to communicate their needs at times. Women said things like, "The nurse would come but leave us for a long time" (Participant [P] 8) and "The nurse never came back" (P 4). Other sentiments were

expressed in statements such as, "I had to keep asking her for things"(P 5) and "She [the midwife] wasn't really around. She was there for the pushing part, but not the for the laboring part"(P2).

The attentiveness category consisted of women's positive statements about the experience. Often the women expressed this in terms of an immediate need that was responded to in a timely manner during childbirth. Statements such as "I would ask for pain medication and they would come right away"(P 9) and "I got my epidural super fast and that was the best thing for me" (P 9) indicate women felt important needs were addressed by the staff. Analyzing the quotes that fell into the category of attentiveness, a clear separation exists whereby women's perceptions about the level of attentiveness by staff was dramatically reduced in the postpartum period. Several women noted feeling like the focus shifted to their babies and not on meeting any of the women's needs, that staff response time was slower, and that they had to ask for help and information much more than during labor and delivery where it was offered freely. Comments such as, "Closer to discharge, I felt like I was getting more and more ignored" (P 6) were verbalized.

"The Staff Was Busy" was articulated many times in the interviews in terms of the women knowing the staff had a lot of other responsibilities and patients. The participants shared their thoughts about maternity staff's apparent work demands, "I guess it was a busy night" (P 1) and " I think the midwife must have been busy" (P 10). When asked why they thought that or how they knew the staff was busy, one woman said, "They all seemed like they had the look of someone who was running around crazily" (P 7). Several others said that the staff told them they were very busy. Others noticed that

the hallways were full of family members of other patients, so they inferred that it was busy the night when that they had their babies.

The underpinnings of the theme "*Needs Are Met in a Timely Manner*" can be looked at through the lens of the Three Delays Model. Specifically, it addresses the third delay of *The Delay in Receiving Adequate Care Once at the Facility* which this paper previously defined as 'Factors for this delay include the availability of equipment, supplies, appropriate staffing, quality of care, and adequacy of a referral system when transport to a facility with a larger scope is required' (Thaddeus & Maine, 1994, p. 1092). Circling back to the intention of this study where RMC serves as the end goal in order to encourage women to seek lifesaving care and thus reduce maternal morbidity and mortality, "*Needs Are Met in a Timely Manner*" serves as a very important theme in terms of creating a definition of respect in the context of maternity care. This will be discussed further in chapter 5.

### **Care is Patient Centered**

The theme of "*The Care is Patient Centered*" consists of the categories:

1) Caregiver Needs versus Patient Centered Care; 2) Having Things Explained; and 3) Feeling Listened To. In these categories, women expressed that the most important things to them essentially came down to having their opinions listened to and considered, being given information and having things explained to them until they were fully understood, and being included in decision-making about the plan of care. More specifically, these ideas related to the concepts of patience/impatience, putting the needs and desires of the patient before the importance of the tasks health workers are required (or want) to do

first, reading birth plans, allowing women to express their voice, and feeling like a valued participant in the process.

Women expressed at times feeling like they were secondary to the tasks or preferences of the staff. This is reflected in statements such as, "I kind of had to argue with the nurse to get her to do it on her shift" 9P 1) and, "She wanted it to be at the beginning of her shift [the birth] instead of the end of her shift"(P 1). One woman expressed dismay when the midwife lamented about her hospital of choice to deliver in, "She was just like pissed off that I wanted to deliver at [hospital A]. Something like, she didn't - like she didn't want to have to go to [hospital A] to deliver my baby. Like she would prefer it at [hospital B]"(P 2). During the postpartum period, several women reported the staff became much more task-oriented than they had been during labor and delivery. One woman stated her thoughts about a maternity nurse, "One was very all about the paperwork"(P 6).

The flipside to this is that many women appreciated feeling like they were the focus of the care and this was what made them rate the care high in terms of respect. They recounted things like how it felt good that the nurse, "asked my permission if it was okay for the student to be there, and letting me know why it was great or important for her" (P 3). Women felt that overall, they were listened to and this was one of the most important things to them. "In terms of respect, I felt they listened to what I had to say and were pretty much zoned in just on me" (P 6) and, "She listened and went along with what we were hoping" (P 3) were both comments that participants made showing they felt valued and cared for. One woman who had said that she came in with a very detailed birth plan was pleased when, "They were respectful in that they read the birth plan"(P 5).

Women expressed that they want to be listened to and have things explained until they could understand them. This came up many times in the interviews in statements such as, "I want to feel like they were willing to listen to whatever and however many questions I had"(P 5) and, "They were good at explaining things and friendly"(P 6), "They were very good at explaining my options and explaining what they suggested and why, and if I had more questions, they happily answered them and stuff"(P 10).

Participants had a few instances whereby they felt excluded from the decision-making process. They described this as scary and disempowering. Participants said, " I don't feel like I was really involved in their conversation"(P 2) and, "I felt like she was maybe not acknowledging my plan"(P 2). A more specific example was when one woman recounted,

I remember her [the doctor] and the midwife kind of whispering back and forth. I think it was necessary to use a vacuum obviously or they wouldn't have used it, but it wasn't like - it wasn't like it was a discussion. It wasn't like I was a part of the decision to use the vacuum (P 2).

### **Overall Feelings of Kindness**

The theme of "*Overall Feelings of Kindness*" was created from the categories: 1) Kindness, Empathy, and Encouragement; 2) Negativity; and 3) Positivity. Within these categories, women expressed that a welcoming demeanor by staff sets the tone for the experience in labor and delivery, that general human decency can have a profound effect on the outcome, and that negative words or sentiments are very harmful, just as positive ones can uplift and empower women while they are in a vulnerable state. Using examples from their own experiences, women told how they felt after being treated a certain way by staff. This was evident from the moment of arrival on the maternity unit.



For example, " I was just kind of taken aback by like - even going upstairs when we arrived to the nurse's station just almost people had like the blank stare or something" (P 4) and, "I felt like a kid getting in trouble for not following the rules [because I did not call before coming] and that was just a bummer"(P 8). One woman offered that, "When I came, if they had been very welcoming it would make me at ease"(P 8). Another stated, "One started asking me, berating me sort of, about why I had not called. And yeah, it felt kind of bad, and sort of like [I was] a child"(P 8).

These ideas were woven throughout the experience in terms of feeling negativity from staff and having it influence how they felt about themselves and their experiences. One participant noted, "I don't know if they were annoyed"(P 4) while another said, "Some of the nurses were a little bit tough love"(P 7). Another still reported, "I just know her body language was extremely closed. Again, I can't remember what it was exactly, I just know I asked a question and she was super snippy and like just no detail what so ever"(P 5).

By contrast, the majority of comments were positive and made women feel taken care of. Comments were generated such as, " Everybody was really, really great"(P 4) and "My overall experience is positive"(P 6). Women noted that, "Women need to have a friendly face and support and feel cared for"(P 8) and, "You want help and someone warm and you know, to like give advice"(P 8). One participant said, "They really had things they said and did that made me feel good and supported"(P 10).

This theme can be explored through the framework of Vulnerability Theory in that all women are exposed to a variable (the experience of childbirth), and their experience in terms of whether they feel strong and positive or conversely, negatively

about it, can be influenced by how external variables such as staff demeanor or actions effect them.

### **Caregivers Are Experts**

The theme of "*Caregivers Are Experts*" is comprised of the categories: 1) Caregivers are knowledgeable; 2) Caregivers are confident; and 3) Expectations Versus Reality. Women expressed that it was important to them in choosing where to seek care that the staff had knowledge and confidence in order to instill a sense of feeling safe. Another feature was that women felt that being prepared for what things in the maternity unit were really like was important, as sometimes their expectations were very different from reality, so they had to adjust their expectations.

A participant said, "I want to go to the hospital and have somebody take care of me, and who knows what's going on"(P 6). Also voiced was, "I feel like they knew what was going on and had all this experience and knowledge and I did not need to know everything going in, it was all okay and they had my back"(P 10). Other examples included, "I just feel like they're confident, like I just felt like they were really experienced"(P 2) and, "The nurses and the midwife were telling me all this stuff that helps and just, it was good to feel like, you know they are on my side and want me to do well"(P 9).

Some women shared negative experiences with caregivers that illustrated the importance of consistent messages from caregivers. Examples women shared included, "Every single person I talked to had a different answer"(P 6) and, "I eventually got fed up with having a different opinion from everybody,"(P 6) and "I had a lot of different nurses

and one would say one thing and another one another thing"(P 8). These encounters did not instill women's trust or confidence in the staff and resulted in women expressing feeling disappointed and frustrated by these situations.

Expectations versus realities of maternity units were an interesting aspect of this study because women come from varied backgrounds and experiences, so a category needed to be created in order to capture comments such as the following statement that a woman made about not having a home visit as part of the postpartum care her provider offered:

My sister-in-law had her midwife come to the house a couple of times post [partum], and I thought that that was amazing, and I kind of thought that that was normal for here. And I remember asking that the first time and I'm like, 'What? You guys don't?' (P 3)

Another woman shared that what she expected she would have to do in terms of convincing staff about her birth plan was not the case, "I was really worried that I was going to be met with a lot of resistance and my concentration would have to be on convincing them that this is what I wanted"(P 5).

One woman explained:

It's so messed up how in the media that like the squeezing someone's hand and screaming and, you know, grinding your teeth and all that stuff that people do on sitcoms, like I could definitely - I definitely wouldn't have been able to give birth if I was doing any of those things (P 7).

These things shape perceptions about what should and should not be in terms of maternity care. These expectations can form ideals of what respect may mean in that context.

### **The Environment is Safe**

The theme of "The *Environment is Safe*" is essentially the embodiment of the code Environment: Safety, cleanliness, and comfort. This consists of the actual physical space women gave birth in and how important that ended up being in terms of a future decision to seek care there (or recommend it to others) to give birth in. Women said, "I liked that I wasn't giving birth in a place where a lot of sick people were"(P 4) and, "I think safety I guess is one of the things that is important to me, but also cleanliness and being comfortable"(P 1). Another stated the positive experience of having privacy, "You get your own suite and you get to stay in the same room as the baby"(P 6). This was not a central theme of the interviews, nor is it the most telling in terms of defining respect in the maternity setting directly. It is, however, important to group as a theme because it indirectly influences how women summarized their experiences and, therefore, addresses the research goal of identifying reasons a woman may (or may not) choose to seek care at a specific facility and what influences their future decision-making.

## **Chapter 5: DISCUSSION**

Women's experiences and perceptions of Respectful Maternity Care (RMC) were explored in this study using a qualitative content analysis design that consisted of interviewing participants as was described in previous chapters. An in-depth discussion of the results that were presented in Chapter 4 will be the focus of Chapter 5 and framed in terms of the original research aim, data drawn from the literature review on RMC and the existing definitions of the term respect in other disciplines, and the theoretical frameworks chosen to guide the researcher in this endeavor. Specifically, The Three Delays Model and Vulnerability Theory will be reflected upon to provide context for the discussion. The strengths and limitations of the study will also be reviewed, as well as conclusions regarding future applications and recommendations for further areas of study.

### **Research Aim**

The purposes of this study were to explore what women who have recently given birth consider respectful care by maternity workers to be; what their experiences of respectful care were during childbirth and the immediate postpartum period and how important this is to them in terms of their ongoing health-seeking behaviors. The qualitative approach used to explore this issue was selected to accomplish this because the extensive literature review showed that there is a gap in terms of what a standardized definition of respect means to women, thereby making it impossible to create interventions to eliminate disrespect and abuse (D&A) and replace it with Respectful Maternity Care (RMC). Specifically, a qualitative method was useful in this regard

because respect is clearly a concept based on individual perception making quantitative methods such as observational processes irrelevant. In trying to elicit a minimum standard that can be applied across populations with nominal localization, the most appropriate method was to allow women to tell their stories and include their opinions and perceptions through interviews. In asking women about: 1) what their perceptions about respect in terms of maternity care are; 2) what their experiences of respectful care were recently while giving birth; and 3) what their thoughts about the importance of experiencing respectful care in their future decision-making about seeking and accessing maternity services are, themes could be identified that can give guidance along a path to eventually defining what respect in the maternity setting means. As was previously described, the themes that emerged were: *1) Needs Were Met In a Timely Manner; 2) Care is Patient Centered; 3) Overall Feelings of Kindness; and 4) Caregivers Are Experts; and 5) The Environment is Safe.*

While the Three Delays Model and Vulnerability Theory were used as a framework, they did not inform the development of the research questions. However, along with the interdisciplinary, historical, and spiritual uses of the concept of respect, they did influence the lens through which the interpretation of the data was conceptualized through. This includes the ideas about where future research could be done in order to eventually develop models and interventions that can be implemented in order to effect improved pregnancy outcomes.

### **Needs Were Met in a Timely Manner**

Building on the idea that the theme of "*Needs Were Met In A Timely Manner*" was synthesized from the categories "Attentiveness" and "The Staff Were Busy" as was explained in Chapter 4, there are many reasons why women expressing the level of responsiveness of staff is connected to their overall perceptions of their experiences as being positive or negative. In terms of what this means for shifting the existing system and finding a definition of respect in this context, there are several notable specific examples that merit further investigation. For example, the fact that there was a perception about the sudden drop-off in the attentiveness of staff occurring once women were in the postpartum period points to the fact that there are potential areas of further research that are warranted so that improvements in clinical care can be implemented.

Another existing gap that further research can address whether or not the decline in care during the postpartum period is a result of staffing patterns, workflow, staff attitudinal issues, or a lack of patient expectation management. Examples of staffing issues are not having enough nurses available for the volume of patients so that limited time is spent with each patient, or a lack of the correct type of specialized staff (such as a lactation consultant) being available to address patients' needs. Workflow problems potentially arise from issues such as task redundancy (such as duplicate charting on many flowsheets that nurses often are required to complete) or ever-widening job scopes reducing time allotted for providing patient care. Staff attitude issues could potentially fall in the realm of barriers to stress reduction due to external factors such as pay, shift assignment, work environment, or lack of access to the supplies required to deliver

proper care. This could also indicate variables that a health worker brings with them as an individual such as gender, ethnic, cultural, or political factors that exist in the broader society outside of the workplace. One final area for possible exploration is that patient expectations of the existing realities of how maternity care is delivered could be addressed before the intrapartum period. As some aspects of maternity care, and the lack of progress therein, are limited by external factors such as resources and governing bodies, it should be acknowledged that not all systems influencing the ability to achieve RMC in totality may be possible in the short term.

*"Needs Were Met In A Timely Manner"* has a direct link to the Three Delays Model in that it illustrates exactly "the delay in receiving adequate care once at the facility"(Thaddeus & Maine, 1994. p 1092). As previously explained, this model was originally designed to address the global problem of maternal morbidity and mortality by delineating where care breakdowns occur. In terms of this study, whereby the participant sample is taken from a high resource setting and was limited to women who had not experienced major complications, the significance of this delay in care lands on the side of the continuum that informs patient satisfaction rather than lifesaving care. This is a limitation of this study that will be discussed later in this chapter. That is not to say that it is not informative in the sense that the issue of how *and* when care is provided are related to RMC along all aspects of the continuum. The perception of women in terms of RMC may shape the definition of respect that ultimately leads to interventions that can influence outcomes positively along the entire spectrum.



### **Care is Patient Centered**

As described in Chapter 4, the theme of "*The Care is Patient Centered*" consists of the categories: 1) Caregiver Needs versus Patient Centered Care; 2) Having Things Explained; and 3) Feeling Listened To. Women expressed these ideas in terms of wanting to have their opinions listened to and considered, being given information and having things explained to them until they were fully understood, and being included in decision-making about the plan of care. This information highlights the fact that the definition of respect in the maternity setting is largely based on the symbiotic relationship between care provider and woman; this echoes the writings of Immanuel Kant who defined the philosophical underpinnings of respect in terms of 'evaluative' respect, the type that is created only when humans interact with each other (Dillon, 2010. section 2.2).

What is interesting about evaluative respect is the idea that it is conditional upon another person's attitudes and actions yet embedded within most training programs for health workers is the idea that health workers should not share their own personal values, views, or experiences with patients. This value continues to be the undertone of healthcare even beyond training programs, and permeates most care delivery systems to the point where it is considered inappropriate or unfavorable to do so. However, the very nature of providing respectful care asks of both parties in an interaction to show their humanity. The question of whether including personal experience as a health worker is central to the theme of "*The Care is Patient Centered*" because, as the literature review explained in Chapter 2, care providers that are more positive, more engaged, and enjoy the experience of work have higher self-efficacy giving way to continued high quality

care (McCullough, Kilpatrick, Emmons, & Larson, 2001). A large part of this cycle is the shared positive experience that needs to be present for respectful care to take place.

To review what Browne described in her definition of respect in the general healthcare setting, there are three aspects which contribute to the creation of respect: 1) nonverbal (such as body language and eye contact); 2) verbal (including demeanor, honesty, and tone); and 3) actions (such as listening, explaining things and giving patients choice) (Browne, 1997). These aspects were clearly articulated in the study sample through examples that several women reported from their experiences. Comments such as, " I could feel they were annoyed and I felt bad"(P 8) express how nonverbal interactions can have a deep impact. "The language that I wanted used was not used"(P 5) is an example of how the details of verbal messaging are important to women. More positively, a concrete example of how one participant explained being treated respectfully was, "The midwife letting me choose my water being broken or Pitocin and answering all the things about the pros and cons of each and that was just really all you could want in that situation"(P 10). All of these examples reiterate what is also an obvious foundational condition of respect, specifically that the concept is deeply rooted in a partnership between two (or more) people.

This fact, therefore, perhaps guides towards a future research question of whether patient-centered means tipping the scales from the current system that is so prevalent in maternity care globally (caregiver centered) to favor the other party (the woman) or whether there is a level of equivalence or partnership that would serve everyone better while developing a standardized model for RMC. Put differently, since the literature shows that the antecedents to disrespect and abuse (D&A) essentially are stress and

burnout, should a key focus be in the creation of work environments that lead to higher self-efficacy and job satisfaction so respectful care becomes the creation of a shared experience between two individuals interacting. This circles back to the notion that those values are raised when care providers are able to participate in an interaction whereby they bring their individual experiences and identities to the table when caring for women. This is in direct opposition to the current culture of healthcare and would require a fairly significant shift.

*"The Care is Patient Centered"* as viewed through the lens of the Three Delays Model gives insight into the important aspects of the first delay, which is *"The Delay in Deciding to Seek Care at A Facility"* As part of the definition of this delay, the perceived quality of care at the maternity facility weighs heavily on a woman's decision whether or not to present for care there (Thaddeus & Maine, 1994, p. 1092). This is critical in that it can correlate with future decision-making regarding where (or if) to seek what could be lifesaving care at a specific place. Another example of why this is important is that it can impact whether or not a woman transports to a facility during an emergency (from a homebirth, for example) when it is appropriate to do so. Women in this study sample were very clear that they wanted to know that the plan of care revolved around their wants and needs; this was evidenced in the fact that all of the participants at some point talked about the high value they placed on having health workers listen to them, explain things to them, and include them in decision-making in some capacity.

## **Overall Feelings of Kindness**

Using the categories of: 1) Kindness, Empathy, and Encouragement; 2) Negativity; and 3) Positivity as the basis for "*Overall Feelings of Kindness*" a discussion on how attitudes, actions, words, body language, and general decency all contribute to the development of a respectful interaction. can be launched. Examples from the interviews included how women were welcomed into the maternity unit (and the tone it set for their overall experience) and the sense of patience (and impatience) they felt from the attitudes and behaviors of the staff.

These ideas echo all of the foundations of morality that the nursing and midwifery professions are based on, the major world religions, and the philosophical roots of respect as noted in Chapter 2. The humanity that comes with several antecedents to respect such as kindness, benevolence, caring, acknowledgement, and compassion proved to be aspects of maternity care that women both expected and described as important to their experiences. Women expressed that the simplest actions, such as offering advice or making them feel like health workers genuinely cared about them were incredibly meaningful to their overall rating of the birth experience. Further, they also expressed that when seeking future services or recommending care at a specific facility to others, a general feeling of being treated kindly was a critical consideration.

## **Caregivers Are Experts**

"*Caregivers Are Experts*" is comprised of the categories: 1) Caregivers are knowledgeable; 2) Caregivers are confident; and 3) Expectations Versus Reality. Every

participant expressed this sentiment to some degree as an important feature in potential future health care seeking decisions. Women expressed clearly that having staff who had knowledge that was reliable was extremely important to them. This falls under the purview of respect because attention to any area that women express as important in terms of providing the experience they are seeking constitutes RMC.

Women especially focused on the issue of knowledge in the postpartum setting where several said they felt they were given a wide variation in answers to various questions and often became confused or frustrated with the inconsistent answers from different staff members. Conversely, when the health worker was confident and consistent information by staff was shared with women, they felt at ease.

Evidence-based practice, a current hot topic in maternity care, is also reflected in the White Ribbon Alliance's Seven Rights of Childbearing Women (Table 1). This was referenced in Chapter 2 and essentially accounts for every woman's right to have access to the highest quality of care available. The creation of that set of rights was developed from a vast body of literature, which is reinforced by this study's sample expressing similar ideals to critical components of RMC.

### **The Environment is Safe**

As mentioned in Chapter 4, "*The Environment is Safe*" is not a theme that directly informs the definition of respect in the context of maternity care. What it does do though, is contribute to women's future decision- making regarding where to seek care (or recommend care providers and facilities to others). In that sense, it is an important thematic topic because when looking at RMC in the broader context of maternal

mortality prevention, women's lives can only be saved if they present for care in a timely manner. This falls into the definition of the First Delay, "The decision to seek care".

Under-utilization of lifesaving services and its relation to mortality has been discussed at length in the literature, and as reviewed in Chapter 2, "*The Environment is Safe*" refers to cleanliness, having the supplies, staff, and knowledge there within to provide care that is evidence-based, timely, and of a quality that instills confidence in the women who seek care there. In the context of Vulnerability Theory, a woman in labor might be less likely to be susceptible to stressors if she has a baseline of confidence in the safety aspects of childbirth (i.e., low risk status), care providers and the unit that she is physically placed.

### **Vulnerability Theory**

By definition to some degree, all pregnant women, and more specifically those within the acute phases of labor, delivery, and immediate postpartum period can be described as part of a vulnerable population. As the physical acts required to give birth take over focus of the body, emotional attention to the process becomes focused as well. This can be viewed as a stressor in part because although the process is natural and from within the woman's body, it can simultaneously constitute an external condition that draws a woman away from her usual state of being and causes her to rely on those around her as part of the experience. This relational dependence is a unique feature of maternity care that complicates the equality often expected (or at least, desired) in most social interactions that lead to a mutual feeling of respect.

As Vulnerability Theory suggests, different people have different responses to similar (or the same) stressors. The variation in response has to do with the same

predisposing factors that likely inform a woman's personal definition of what constitutes respect in a given situation. Examples of this are cultural, political, reflective of gender roles within society, religious beliefs, or socio-economic level in nature. The concepts of resiliency and susceptibility become descriptors in this sense and are essentially dictated by these contextual variables that the stressor occurs within. In terms of this study sample, the variables of maternity care and how staff manage interactions with women during this time adds another layer of context.

The level of vulnerability, susceptibility, and resiliency that an individual experiences can also be seen in all of the foundational disciplines explored earlier in this paper. Namely, philosophy, religion, nursing, and midwifery all are rooted in the concept of looking at people holistically in addition to the contextual environment they are acutely in. The observation that women all expect to be treated with compassion are hallmarks of nursing and midwifery based on the ideal of morality. Within the context of religion, this is often expressed as a focus on eliminating suffering in vulnerable people. Philosophy teaches us that this is expressed in both an attitude and the actions of a person towards another. When folded into an individual over time, these ideals become part of the fabric of who they are and how they perceive interactions with others.

### **Definition of Respect in the Maternity Setting**

While it is obviously not possible to distill a standardized definition of respect in the context of maternity care from one study, within this participant group several factors were consistently woven throughout that can inform what could be used as the building blocks for a working definition. Namely, the key features that women expressed that

were important to them in shaping the experience as positive or negative included having the care be centered around their desires, being listened to, and having things explained to them. Also critical was that staff should emit a general sense of kindness, the physical space should be clean and safe, care should be evidence-based, and women's needs should be attended to in a timely manner. All of these factors orbit around the underlying conclusion that it is the relationship that a woman can create with those taking care of her that is important; the simple act of human interaction with people who see her as an equal partner in her experience holds the key. Therefore, the working definition of respect that can be derived from this study and its resulting themes is “Respect in the maternity setting is a multivariate concept based on women feeling well cared for by health workers through their attitudes and actions: attentiveness, a high level of knowledge, kindness, a focus on patient preference, and providing a safe environment to put women at ease.”

The more esoteric questions that these factors lead one to consider are where the line between a health worker not giving enough of themselves to create equivalency (as is the current norm in health professions) and where the line has been crossed too far resulting in stress and burnout. Women certainly have expectations of partnership when thinking of maternity care in terms of respect; maternity staff certainly has a need to protect themselves from the intensity of being part of such interactions with multiple patients all day, every day at work. This would be a good area to explore in the quest to define respect in maternity care within the context of avoiding staff's stress and burnout.



## **Limitations**

Some of the limitations of this study were anticipated while others were only identified retrospectively. As was discussed earlier, birth is the combination of physical, emotional, psychological and social factors, many of which precede pregnancy but still bring biases, ideals, and beliefs to the childbearing process for each person. For example, a woman who has a deep concern that she will not be listened to when she comes to the hospital because she has experienced that before (even in another medical setting when not pregnant) may be very defensive upon arriving at the maternity unit and, thus, elicit more negative responses from staff than one who is trusting. In this sample, previous experiences within healthcare (including prenatal visits), prior history of abuse in general, and other factors that may cause mistrust were not assessed or discussed directly with participants.

The urgent, unpredictable, and variable elements of the nature of birth can influence demeanor, attitude, and actions by staff towards patients. For example, complications that arise during the course of labor or delivery can alter the prioritizing by maternity staff of things like explaining procedures and listening to patient desires before acting. This study did not include participants that experienced major complications, so no conclusions can be made regarding the variability that can occur under those circumstances.

Santa Cruz County has its own specific local culture and style of maternity care which is not likely to be generalizable to many other populations. Specifically, patient-centered care was already the norm in the study area and every facility can be categorized as a high resource setting with full staffing and supplies. Further, birth plans, the use of

doulas, and local prenatal education programs contribute to high patient satisfaction rates in general at all facilities in Santa Cruz County. These factors led to a small sample size as participant experiences were similar and mostly very positive, so saturation was reached very quickly. Also, because the experiences of the study sample were mostly all positive, the research question which intended to explore whether respectful care informs and influences future decision-making about where to seek maternity health services was difficult to assess.

### **Implications for Clinical Practice**

The implications for clinical practice for this study have a wide reach. Each theme gave rise to its own set of considerations, particularly when viewed through the frameworks of the Three Delays Model and Vulnerability Theory. "*Needs are Met in a Timely Manner*" asks facilities to look at staffing, workflows, and health worker attitudes and behaviors. Particularly when addressing attentiveness and busyness, the approach should be three-pronged as those are functions of having enough staff to meet the patients' needs, making sure the staff are using their time efficiently enough to fulfill all work duties in the defined work time, and assuring that any stress from overwork does not flow into the care they provide.

"*Care is Patient Centered*" and "*Caregivers Are Experts*" and "*The Environment is Safe*" all speak to the importance of evidence-based practice being central to care that is provided in the maternity setting. This means that staff must not only be proficient in skills and have knowledge, but their demeanors and actions must portray confidence, patience, and provide enough humility that women feel they are partners in their care.

"*Overall Feelings of Kindness*" serves to reinforce the focus that needs to be placed on those demeanors and actions reflecting kindness since they can set the tone for a woman's entire experience and future decision making about healthcare.

### **Future Research**

Using the building blocks for a working definition of respect in the maternity setting, maternity staff training programs should begin to incorporate discussions about boundaries, humility, patient centered care, and attitudes into the pre-service setting. Facilities should offer ongoing training to staff on these very issues. Tools such as patient satisfaction tools could continue to monitor the value of these practices. Additionally, further research should attempt to replicate this study (or a variation thereof) in order to refine the working definition of "Respect in the maternity setting is a multivariate concept based on women feeling well cared for by health workers through their attitudes and actions: attentiveness, a high level of knowledge, kindness, a focus on patient preference, and providing a safe environment to put women at ease." This could be done in a variety of populations, including low resource settings which would likely capture a wider range of women's experiences along the continuum of D&A. Even repeating this study with the aim of attracting a broader base of participants in Santa Cruz County would reaffirm the study findings. Another avenue for expansion of this body of research would be to include experiences in the prenatal setting as it very likely informs pre-existing attitudes before women enter the childbearing process, particularly in obstetric practices where the same providers care for women throughout the entire pregnancy and childbearing process.

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## TABLES

**Table 1. Seven Rights of Childbearing Women**

Category of Disrespect and Abuse <sup>1</sup>		Corresponding Right
1.	Physical abuse	Freedom from harm and ill treatment
2.	Non-consented care	Right to information, informed consent and refusal, and respect for choices and preferences, including the right to companionship of choice wherever possible
3.	Non-confidential care	Confidentiality, privacy
4.	Non-dignified care (including verbal abuse)	Dignity, respect
5.	Discrimination based on specific attributes	Equality, freedom from discrimination, equitable care
6.	Abandonment or denial of care	Right to timely healthcare and to the highest attainable level of health
7.	Detention in facilities	Liberty, autonomy, self-determination, and freedom from coercion

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**Table 2. Births by Ethnicity, Santa Cruz County 2014**

Ethnicity	Percent of Total Population	Percent of Live Births
White	57.8%	38%
Latina	33.7%	56%
Asian/Pacific Islander	4.5%	3%
Black	0.9%	0
Other	3.1%	3%

Adapted from US Census Bureau: Santa Cruz County, 2010. Retrieved from [https://factfinder.census.gov/faces/nav/jsf/pages/community\\_facts.xhtml?src=bkmk](https://factfinder.census.gov/faces/nav/jsf/pages/community_facts.xhtml?src=bkmk)

**Table 3. Births by Age, Santa Cruz County 2014**

Age Group	Percentage of Live Births
<14	0.1%
15-19	5.5%
20-24	16.4%
25-29	23.5%
30-34	30.2%
35-39	19.2%
40-44	4.8%
>45	0.2%

Adapted from US Census Bureau: Santa Cruz County, 2010. Retrieved from [https://factfinder.census.gov/faces/nav/jsf/pages/community\\_facts.xhtml?src=bkmk](https://factfinder.census.gov/faces/nav/jsf/pages/community_facts.xhtml?src=bkmk)

**Table 4. Births by Mode of Delivery, Santa Cruz County 2014**

Mode of Delivery	Percentage of Live Births
Primary Cesarean	16%
Repeat Cesarean	15%
Vaginal	68%
Vaginal Birth After Cesarean	1%

Adapted from US Census Bureau: Santa Cruz County, 2010. Retrieved from [https://factfinder.census.gov/faces/nav/jsf/pages/community\\_facts.xhtml?src=bkmk](https://factfinder.census.gov/faces/nav/jsf/pages/community_facts.xhtml?src=bkmk)

**Table 5. Ethnic Makeup of Participants n=10**

	White	Latina	Other
N	7	2	1
% of sample	70%	20%	10%
% in births in Santa Cruz County overall	38%	56%	6%

Adapted from US Census Bureau: Santa Cruz County, 2010



**Table 6. Age Distribution of Participants n=10**

	<b>25-29</b>	<b>30-34</b>	<b>35-39</b>	<b>40-44</b>
<b>N</b>	1	5	3	1
<b>% of sample</b>	10%	50%	30%	10%
<b>% in births in Santa Cruz County Overall</b>	23.5%	30.2%	19.2%	4.8%

Adapted from US Census Bureau: Santa Cruz County, 2010

**Table 7. Mode of Delivery of Participants n=10**

	<b>Vaginal Delivery</b> (Census data does not differentiate SVD vs assisted vaginal delivery)	<b>Primary Cesarean</b>	<b>Other (VBAC and repeat Cesarean)</b>
<b>N</b>	9	1	0
<b>% of sample</b>	90%	10%	0
<b>% in births in Santa Cruz County Overall</b>	68%	16%	16%

Adapted from US Census Bureau: Santa Cruz County, 2010

## **Appendix A: Interview Guide**

### ***A. What are women's perceptions about respect in terms of maternity care?***

What are some examples of things a maternity worker (doula, nurse, midwife, doctor) might say or do when caring for women during labor and delivery that would show respect?

What are some things that maternity workers might say or do when caring for women during labor and delivery that might show disrespect?

When thinking about labor and delivery, what does 'respectful care' mean to you?

How do you think respect during labor and delivery is different than respect in other circumstances (if at all)?

### ***B. What were the experiences of respectful care of women who have recently given birth?***

Thinking back to your most recent labor and delivery, what are some things that maternity workers said or did that made you feel respected?

Thinking back to your most recent labor and delivery, what are some things that maternity workers said or did that made you feel disrespected (if anything)?

When you think of your most recent experience giving birth, do you generally think of it as a negative or positive experience?

If your experience was generally positive, what things were most important to contributing to that feeling of positivity?

If your experience was generally negative, what things were most important to contributing to that feeling of negativity?

### ***C. What are the thoughts of women about the importance of respectful care in decision-making about seeking and accessing future maternity services?***

Would you refer your friends and family to give birth in the same place (or with the same providers) as your most recent birth and why, or why not?

If you were to get pregnant again, would you give birth in the same place (or with the same providers) as you did with your most recent birth?

What would you say are the most important factors in deciding where you give birth and with which providers?

## Appendix B: Informed Consent

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### *Sutter Maternity and Surgery Center, Santa Cruz, California*

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#### INFORMED CONSENT TO ACT AS A RESEARCH PARTICIPANT

**The Principal Investigator is Cindy Stein and the sub-investigator is Dr. Maureen Shannon**

**This study was explained to you by: Cindy Stein**

**You are being asked to participate in a research study. Research studies include only people who choose to take part. Please take your time to make your decision about taking part. You may discuss your decision with your friends and family. You can also discuss it with your health care team. If you have any questions, you can ask your study doctor for more explanation.**

**You have been asked to participate in this research study because you have given birth in Santa Cruz County in the last 6 months, are over 18 years old, speak and read English fluently, and are willing to share your experiences giving birth.**

#### **A. WHAT IS THE PURPOSE OF THIS STUDY?**

**The purposes of this study are to:**

- 1) To try to standardize a definition for respect by health workers in the maternity setting*
- 2) To explore whether or not, and to what degree, your previous experiences or perceptions of treatment by maternity health workers in Santa Cruz County play a role in your future healthcare seeking choices.*

*The reason for this is because research has shown that women who have positive experiences with maternity staff while giving birth are more likely to return for care or refer friends and family for services. Women who had a bad or negative experience may delay or avoid seeking maternity services in the future. This is important because in many settings, women who avoid or delay seeking treatment for pregnancy and birth complications are at higher risk of having complications which could have been prevented or treated appropriately.*

*Research from other regions of the US and the world has shown that women are often treated disrespectfully or even abused while giving birth in many settings for a variety of reasons. Introducing the concept of respect into maternity staff training and hospital policies is one way to fix this. However, respect has different definitions from person to person. This study aims to help create a standard definition of respect in the maternity setting to improve care for women in Santa Cruz County and ultimately, around the world.*

**B. HOW MANY PEOPLE WILL PARTICIPATE?**

**About 15 to 20 participants will take part in this study.**

**C. HOW LONG WILL I BE IN THIS STUDY?**

If you agree to take part in this study, your involvement will include:

- Selecting a place and time you feel comfortable meeting with the researcher
- Filling out a very brief questionnaire with items including your age and how many children you have
- Spending approximately 1 hour answering questions about the study topic with the researcher
- Possibly being contacted by the researcher at a later date by telephone to very briefly clarify any of your comments or answers which may need follow up
- You will receive a printed copy of the final study results at the completion of the study

**D. WHAT WILL HAPPEN TO ME DURING THIS STUDY?**

Once you choose where and when you will meet with the researcher, you will fill out a very short survey (questionnaire) and then the following interview guide will be used to guide the conversation but more specific questions relating to these topics will be asked. You will be able to discuss any topics you choose as well. It is also your right to decline to answer any questions or choose to terminate your participation in the study at any time (even if the interview is not completed).

1. What are your perceptions about respect in terms of their maternity care?
2. What were your experiences of respectful care when you recently gave birth?
3. What are your thoughts about the importance of experiencing respectful care in your future decision-making about seeking and accessing maternity services?

Interviews will be recorded and transcribed but you will be assigned a study ID number so your name and any other important information (such a phone number, etc...) will not be recorded. Nobody will be present at the interview other than the researcher (and your baby if you choose to bring him/her). The researcher will analyze the transcripts by grouping key words from all the interviews into themes and create a narrative to answer the research questions. A specified number of interview transcripts will be independently reviewed by a content expert familiar with the topic to determine codes, categories and themes are accurate. This content expert will be Dr. Maureen Shannon of the University of Hawaii at Manoa, who also serves as the researcher's PhD committee chair.

## **E. WHAT ARE THE RISKS OF THIS STUDY?**

This study carries minimal risk. Your participation is entirely voluntary. Your personal information will not be identified on any study documents and will take place when and where you choose so as to maintain your privacy. Of the potential minimal risks include the possibility that some women may find some of the topics of a very personal nature. This could cause shame, embarrassment, or emotional trauma. In order to avoid this, you should know that you can decline to answer any questions you do not want to answer and/or terminate participation in the study at any time even if the interview is not completed.

Another potential risk is that maternity staff at the facility may feel threatened or nervous about the nature of the study thinking that it is intended to judge performance and behavior. In order to eliminate this risk, notices will be posted in the private area of the maternity units of all facilities where participants may have received maternity services to explain the nature of the study.

The specific components of protecting your privacy include:

- 1) You will select your own time and place to be interviewed.
- 2) Nobody but you and the researcher will be present for the interview (unless you choose to bring your baby).
- 3) You will be assigned a study identification number that will be used for the duration of your involvement in the study instead of your name.
- 4) Your medical record/health information will not be accessed at any time as part of this study.
- 5) The interviews will be recorded and then transcribed. A professional transcriptionist will be used for this. The transcriptionist will be asked to sign a confidentiality agreement, which will include that all materials from the study are to be returned to the researcher and no copies of any of the research materials can be made at any time.
- 6) All data collected as part of the study will be kept on the researcher's password-protected laptop in an encrypted file and accessible only to the researcher.
- 7) Signed written informed consents will be stored in a locked filing cabinet separate from the data collected to further ensure confidentiality.
- 8) All research materials will be destroyed after the completion of the study.

## **F. WHAT ARE THE POTENTIAL BENEFITS TO ME AND OTHERS?**

The benefits of this study are threefold. 1) You will be given the chance to tell and process their birth stories, which has been shown to be enjoyable and positive psychologically for women who recently gave birth. 2) Health workers in the maternity setting in Santa Cruz will get performance feedback from recent patients. 3) Policies can be designed to improve maternity care and patient outcomes.

Additionally, a working definition of the concept of respect in the maternity setting can be replicated and localized to other regions in order to continue to refine the definition and move towards standardization of care.

**G. WHAT OTHER ALTERNATIVES OR TREATMENT OPTIONS ARE AVAILABLE TO ME?**

You are free to decline participation at any time, decline to answer any questions asked during the course of the study, or terminate your participation in the study at any time. Your participation is entirely voluntary.

**G. WHAT HAPPENS IF I AM INJURED OR HARMED IN SOME WAY BY THE STUDY?**

While there is almost no risk of this, you can contact the researcher with any concerns about the study or negative consequences you suffered as the result of participation. Alternately, you can contact Sutter Review Board or The University of Hawaii at Manoa School of Nursing.

**I. HOW CONFIDENTIAL ARE MY RECORDS?**

- You will select your own time and place to be interviewed.
- Nobody but you and the researcher will be present for the interview (unless you choose to bring your baby).
- You will be assigned a study identification number that will be used for the duration of your involvement in the study instead of your name.
- Your medical record/health information will not be accessed at any time as part of this study.
- The interviews will be recorded and then transcribed. A professional transcriptionist will be used for this. The transcriptionist will be asked to sign a confidentiality agreement, which will include that all materials from the study are to be returned to the researcher and no copies of any of the research materials can be made at any time.
- All data collected as part of the study will be kept on the researcher's password-protected laptop in an encrypted file and accessible only to the researcher.
- Signed written informed consents will be stored in a locked filing cabinet separate from the data collected to further ensure confidentiality.
- All research materials will be destroyed after the completion of the study.

**J. IS BEING IN THIS STUDY VOLUNTARY?**

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

**K. WILL I BE PAID FOR PARTICIPATING?**

No, you will not be paid for participating in this study.

**L. WHO IS FUNDING THIS STUDY?**

This study is not funded. It is part of the PhD requirements for the primary researcher Cindy Stein who is a student in the PhD program at University of Hawaii in the School of Nursing. Her committee chair and the graduate department chair is Dr. Maureen Shannon.

**M. WILL IT COST ME ANYTHING TO BE IN THIS STUDY?**

No, there is no cost to participate.

**N. WILL I RECEIVE NEW INFORMATION ABOUT THE STUDY WHILE PARTICIPATING?**

You will receive a copy of the final study from the researcher in print once it is completed.

**O. EXPERIMENTAL SUBJECT'S BILL OF RIGHTS**

**A copy of the Experimental Subject's Bill of Rights and a copy of this consent form will be given to you for your own use.**

**P. WHAT IF I HAVE QUESTIONS?**

We encourage you to ask questions. If you have any questions about the research study itself, or to report an injury from the research, please contact: *Cindy Stein 808-381-0959*

Should you have any questions about your rights as a research participant, you may call the Sutter Health Institutional Review Board, which is concerned with protection of volunteers in research projects, at (925)-287-4052 or by writing: Sutter Health Institutional Review Board Office, 2121 N. California Blvd, Suite 310, Walnut Creek, CA 94596.

<b>SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE</b>
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**I have read (or someone has read to me) the information provided above. I have been given an opportunity to ask questions and all of my questions have been answered to my satisfaction. I have been given a copy of this consent form; the Subject's Experimental Bill of Rights; and a copy of the Authorization for the Use and Disclosure of Protected Health Information for Research form.**

**BY SIGNING THIS FORM, I WILLINGLY AGREE TO PARTICIPATE IN THE RESEARCH IT DESCRIBES.**

Participant's Name	Date
Participant's Signature	Date
Name and Signature of Person Conducting Consent Discussion	Date



## Appendix C: Demographic Questionnaire

Please answer the following questions:

**1) Please circle your age category:**

<14  
15-19  
20-25  
25-29  
30-34  
35-39  
40-44  
>45

**2) Please circle the ethnicity you most closely identify with:**

White  
Latina  
Asian/Pacific Islander  
Black  
Other \_\_\_\_\_

**3) Number of pregnancies you have had total \_\_\_\_\_**

**4) Number of live births you have had total \_\_\_\_\_**

**5) Mode of delivery for your most recent birth:**

Vaginal Delivery  
Assisted Vaginal Delivery (vacuum or forceps)  
Cesarean

## **Appendix D: Recruitment Script**

### Recruitment Script

Hello, my name is *Cindy Stein* and I am a PhD student at the University of Hawaii at Manoa School of Nursing. I am also a midwife here at Sutter. I am currently working on a study to complete my dissertation. I am studying women's experience giving birth in terms of how respected they felt by staff during childbirth and am recruiting participants. This research will hopefully lead to a better understanding of how to create safe and respectful environments in which women want to seek care while giving birth.

If you volunteer as a participant in this study, you will be asked to spend one hour being interviewed by me about your recent experience giving birth and your individual definition of what respect means to you. You will also be asked to fill out a short demographic survey.

You will be able to pick the time and place of the interview. All personal information and answers to the interview questions will remain confidential.

I would like to assure you that this study has been reviewed and received ethics clearance through the Sutter Internal Review Board. However, the final decision about participation is yours.

I am searching for participants who have given birth in the last 6 months (even if not here at Sutter), speak and read English fluently, are over 18 years old, and did not receive any medical care from me prenatally, during labor and delivery, or at any point afterwards. If you are interested in participating, please fill out one of the individual confidential recruitment cards\* and I will be in touch with you, or you can take one of my cards and contact me directly via text, phone, or email.

Thank you

### Appendix E. Codes, Categories, Themes and Definitions

Codes	Categories	Themes and Definitions
<p><b>“Attentive”</b></p> <p>“They were very attentive.”</p> <p>“She was great, she was very good at checking in with me and seeing how things were going and explaining all of the options and stuff.”</p> <p>“The nurses were great on the postpartum floor. They came when I rang the call bell, they were on top of like giving me Advil.”</p> <p>“She really took her time, which was great.”</p> <p>“Grateful that there were so many people helping, and that they had enough staff and stuff.”</p> <p>“I got my epidural super-fast and that was you know the best thing for me.”</p> <p>“I liked all the people, I just think it was all fast paced and hectic and that was a shock to me.”</p> <p>“I would ask for pain medication and yeah they came right away.”</p> <p>“She was really attentive.”</p> <p>“The entire floor was empty except for one other lady which is why I probably got a lot of attention from the nurses.”</p> <p>“The midwife just wasn't around.”</p> <p>“The midwives they come each morning but very quickly.”</p>	<p><b>Attentiveness</b></p> <p>(n= 20 statements)</p>	<p><b>Needs Are Met in a Timely Manner</b></p> <ul style="list-style-type: none"> <li>• Consists of “Attentiveness” and “The Staff Was Busy”</li> <li>• “The Staff Was Busy” was built from the in vivo codes “abandoned” and “ignored”</li> <li>• Three Delays Model</li> <li>• Midwife not there, nurses do most care</li> <li>• Less care in postpartum period than desired</li> <li>• Women felt staff was available to care for them and met their needs in a timely manner</li> <li>• Women knew the staff was busy</li> </ul>

<p>“The nurses were there and the whole time just really on it.”</p> <p>“There was one who like, sat with me for a long time and helped and saw I was on the verge of tears and just really was awesome.”</p> <p>“They came in and checked on me frequently.”</p> <p>“They gave me like handouts and she would come at odd times and explain things but then, like I was sleeping and remembered or understood nothing and she would leave again.”</p> <p>“They left, and I had ten questions and - that'd be my only complaint.”</p> <p>“They were pretty much there in and out of the room quite a lot and checking up on me and making sure I was feeling okay and asking if there's anything I could do.”</p> <p>“We had a bigger conversation later and she really took her time, which was nice.”</p> <p>“When I asked for things they got it.”</p>		
<p><b>Busy</b></p> <p>“I guess it was a busy night.”</p> <p>“I know nurses are doing so much stuff.”</p> <p>“Maybe to make it better, maybe having people feel more slowed down when they're in a room.”</p> <p>“It was a long long time I was in the bed and she left and did not come back for a long time, and uh, it seemed very busy there and she finally came back.”</p>	<p><b>Staff Was Busy</b> (n= 29 statements)</p>	

<p>“I eventually called directly, and I think they were super busy.”</p> <p>“They may have been short staffed during the time that I was there or something.”</p> <p>“I guess it got pretty busy, and so they moved us to the new side [other unit in the hospital].”</p> <p>“I think she told me she was busy.”</p> <p>“She apologized for leaving me a long time before putting the IV in and so, I knew that.”</p> <p>“I think the midwife must have been busy.”</p> <p>“I think they all try their best even when it is busy they really try and be there for you in that moment you need them.”</p> <p>“I think they were really busy.”</p> <p>“I understand they are busy and I do think the nurse, she tried, and was like I will get you settled and then we can try some things.”</p> <p>“The nurse, she was nice, but she was really busy.”</p> <p>“The staff was busy.”</p> <p>“They also seemed like they had the look of someone who was running around crazily, so...”</p> <p>“They told me that they were busy.”</p>		
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<p><b>“Abandoned”</b></p> <p>“They left, and I had ten questions and – that’d be my only complaint.”</p> <p>“She never came back [after asking the nurse for help].”</p> <p>“The midwife just wasn't around.”</p> <p>“She was there for the pushing part [the midwife], but she wasn't there for the laboring part.”</p> <p>“She wasn't really around [the doctor].”</p> <p>“The midwife came back like later then she said and just I think in general I was surprised how little I saw her I guess.”</p> <p>“The nurse would come but then leave us for a long time.”</p> <p>“If your appointment is not for six weeks, a lot can happen in that six weeks that's is scary.”</p>		
<p><b>“Ignored”</b></p> <p>“Closer to discharge, I felt like I was getting more ignored I guess.”</p> <p>“Had to keep asking for things.”</p> <p>“ I felt like I couldn't be maybe asking for things as much down there [on the postpartum unit].”</p> <p>“I kept asking for one [a lactation consultant] and they were like, oh well she's doing this, oh she's over here; she has to go to teach a class.”</p>		

Task focused (staff)	Caregiver Needs v. Patient-Centered (n= 23 statements)	Care is Patient Centered
<p>“One [nurse] was very all about the paperwork.”</p> <p>“She wanted it [my delivery] to be like at the beginning of her shift instead of the end of her shift.”</p> <p>“I kind of had to argue with the nurse to get her to do it on her shift.”</p> <p>“I felt rushed when I was getting ready to leave like, ok they wanted the room urgently and it felt like, sort of I overstayed my welcome.”</p> <p>“I mean, at first, was really jarring, especially like the morning after giving birth was like, "I've barely slept, and you want to talk about a birth certificate?"</p> <p>“I thought it was weird there were a lot of people in and out all the time and that was hard to rest and also just, I had no idea who most of them were.”</p> <p>“She was totally just paying attention to the technology and not necessarily the patient.”</p> <p>“The nurses have to do a lot of things and it’s like overwhelming with all the exams and blood pressure and forms and instructions and they do all this testing on the baby and so many people come to see you nurses, midwife, pediatrician, lactation, hospital paperwork people, like um, maybe insurance people, and the hearing test for the baby. It’s a lot. “</p> <p>“There was one who just, oh she would ask about papers and birth certificates and she just seemed very focused on the tasks and not on me.”</p>		<ul style="list-style-type: none"> <li>• Consists of “Caregiver Needs vs Patient Centered Care”, “Having things Explained”, “Feeling Listened To”</li> <li>• “Caregiver Needs vs Patient Centered Care” built from in vivo codes “Task Focused” and “Annoyed”</li> <li>• Patience/impatience</li> <li>• Philosophy, religion, nursing foundational concepts</li> <li>• Women expressed the importance of having a voice in their care</li> <li>• Birth plans were read</li> <li>• Was important staff included them in plan</li> <li>• The value in understanding and having things explained</li> <li>• Putting the patient needs before the task work of providing services</li> </ul>

<p>“It was like, she had to do her job first and get all the tasks done before I could ask for things I wanted.”</p> <p>“One was very all about the paperwork.”</p> <p>“Other people who would pop in and ask questions or ask the nurse things or I mean, they had hospital clothes on so they worked there but it was weird and hard to rest .”</p> <p>“She offered the tub and shower and some other ideas but they were deferred until all the logistic stuff was done first.”</p> <p>“She wanted it to be like at the beginning of her shift instead of the end of her shift [the birth].”</p> <p>“It was distracting but I know she has a job she has to do.”</p> <p>“They have tasks and they have a different speed.”</p> <p>“They were more about her [the baby and the tests for her] and less about me about the time we got to leaving.”</p> <p>“They were nice but it becomes this busy job type of thing after the baby is born instead of the supporting nurturing stuff that happens in labor.”</p>		
<p><b>Annoyed (staff with woman)</b></p> <p>“She [the midwife] was just like pissed off that I wanted to deliver at [hospital A]. Something like, she didn’t – like she didn’t want to have to go to [hospital A] to deliver my baby. Like she would prefer it at [hospital B].”</p>		



<p>“We were trying to get our stuff loaded or [my husband] was leaving to deal with something. I can't remember what it was. But, it was taking us longer to get packed up and she kind of seemed annoyed.”</p> <p>“I kind of felt this like - not annoyed energy, but kind of exasperated.”</p> <p>“I could feel they were annoyed and I felt bad.”</p> <p>“I don't know if they were annoyed.”</p>		
<p><b>Having Things Explained</b></p> <p>“I feel like the baby care was the focus and I understand that and but I was like, hmm ok so now I am a patient too still and nobody is patient when I ask things about like my bleeding and it's just like-ok yeah yeah that looks fine but no guidance.”</p> <p>“Letting me know or asking my permission if it was okay for the student to be there, and letting me know why it was great or important for her.”</p> <p>“The midwife letting me choose my water being broken or Pitocin and answering all the things about the pros and cons of each and that was just really all you could want in that situation.”</p> <p>“Some more like all business and others treated me more like a person [when it came to explaining things].”</p> <p>“The attending pediatrician was just a little more like informal than I was comfortable with, [in explaining things] and especially being a new mom.”</p> <p>“[I used the] nitrous and like it didn't do anything for me. And I feel like afterwards, they were like, "Oh, yeah, a lot of people say that." I was like,</p>	<p><b>Having Things Explained</b> <b>(n= 30 statements)</b></p>	

<p>"You could of told me ahead of time and we would of just skipped that and gone straight to the Fentanyl."</p> <p>"And they explained the options I had, like a drug aide or any pain aides and all that kind of stuff pretty well."</p> <p>"Everything was so quick, and they explained everything, but I need it like three times because of everything that's going on."</p> <p>"Explain things to me, let me decide things, empower me, be friendly, take the time."</p> <p>"[They] explained the pain level."</p> <p>"I felt like they were used to dealing with people that wanted much more explanation."</p> <p>"I just felt like she sincerely wanted me to understand what she was doing and teach me and how to care for this newborn."</p> <p>"I just wanted to talk to the doctor, it wasn't like offered to me or anything. I had to like be like, no, I want to talk to the doctor, to know what the side effects are."</p> <p>"I remember her and the midwife kind of whispering back and forth."</p> <p>"I think it was necessary to use a vacuum obviously or they wouldn't have used it, but it wasn't like - it wasn't like it was like a discussion."</p> <p>"I would ask things and they would say ok here are your options, these are the things you can choose and why."</p>		
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<p>“I’m very kinesthetically minded. So if you tell me what to do, I can do it, physically. And so it was super. She was really specific and it was super helpful.”</p> <p>“If I had questions it was always like someone would really tell me what is going on.”</p> <p>“[It] made me a little bit worried [wondering] why are there so many people in here?”</p> <p>“She explained it all.”</p> <p>“She just kind of walked me through like what the levels pain could be and stuff because I was trying to minimize it a lot.”</p> <p>“She talked about everything she was doing, she explained everything she was doing.”</p> <p>“She troubleshooted with me. She gave me options.”</p> <p>“They answered every question I had.”</p> <p>“They explain things and let you feel like you are part of the equation and not just an object to be dealt with.”</p> <p>“They were good at explaining things and friendly.”</p> <p>“They were like, “Okay, well you had a C-section, here’s how to like survive in the hospital,” but like there wasn’t a whole lot of, “This is what you do when you get home.”</p>		
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<p>“They were very good at explaining my options and explaining what they suggested and why, and if I had more questions, they happily answered them and stuff .”</p> <p>“[I thought] wait a second. That doesn't seem right." So, I kept asking .”</p> <p>“We just had a brand-new baby and we have no idea how to take of like - you can't just be like, "Oh, you'll be fine."</p>		
<p><b>Feeling Listened To</b></p> <p>“I don't feel like I was really involved in their conversation.”</p> <p>“I felt like she was maybe not acknowledging my plan.”</p> <p>“I kind of like had argue with the nurse to get her to do it on her shift.”</p> <p>“It was very empowering to feel a part of choosing things even though they are the experts.”</p> <p>“It wasn't like I was a part of the decision to use the vacuum.”</p> <p>“Knowing what the patient's goals are, I guess. So, that you're all in the same, like their understanding of what's going on in the situation.”</p> <p>“They asked me what things I wanted and did not want and took time to find out who I am a little.”</p> <p>“They were respectful in that they read the birth plan.”</p>	<p><b>Feeling Listened To</b> <b>(n= 25 statements)</b></p>	

<p>“They're looking out for us and not just, "Well, this is how things are done and this is how I've been trained, and this is what the literature shows, and this is how we do things here."</p> <p>“You should go somewhere that they want to cater to your desires and not just-oh we have a system and we know best so you should just do what we say. That would be disempowering and not feel good.”</p> <p>“We had a very detailed birth plan .”</p> <p>“Being like truly listened to.”</p> <p>“But I was like, I'm very sensitive to medication and [the midwife] listened to me.”</p> <p>“But in terms of respect, I felt they listened to what I had to say and were pretty much zone in just on me.”</p> <p>“I feel like she listened to me, and we had a birth plan and she read it.”</p> <p>“I felt like a person and if I had a worry or something, then these are people who would listen.”</p> <p>“I had had really good experiences with [the hospital] but previously with going to doctors in other places, I had had really bad experiences of not being listened to.”</p> <p>“I think to give birth, to have the best outcomes for birth and the best birth experience, you have to feel like you're heard, you're being listened to.”</p> <p>“I want to feel like they were willing to listen to whatever and however many questions I had.”</p>		
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<p>I would want to feel like any time I had an interaction with my care provider, I wouldn't want to feel rushed and I wouldn't want to feel like, again, not listened to.”</p> <p>“If I get listened to and we talk about the plan and I know what is happening and also, just a smile or being warm.”</p> <p>“If they listen to you then you feel like you are part of this instead of it just like, happening to you.”</p> <p>“Listening to me was important, I think I would go back because that seemed sort of a universal thing there, like you can expect you will not be ignored.”</p> <p>“Listening to me. I find in allopathic medicine that is often what I feel like does not happen. I don't feel listened to.”</p> <p>“She listened and answered my questions she sat down and was not giving me the vibe that she wanted to get out of the room and do other things.”</p> <p>“She listened and went along with what we were hoping.”</p> <p>“The only thing that I really feel like I didn't get listened to is with nursing.”</p> <p>“They also were saying it's going to hurt anyway. And I was like, I know it's going to hurt, but I have really good body awareness and I'm not a whiner.”</p> <p>“They were like, ok yes let's do our things fast to get you want you need and that felt like, they really listened to me.”</p>		
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Kindness	Kindness, Empathy, and Encouragement (n=28 statements)	Overall Feelings of Kindness
<p>“I didn't really want to talk about it, but she kind of pushed me through it.”</p> <p>“I feel like things that helped me were feeling supported.”</p> <p>“I leaned on her and she held me, and then we would take one or two steps between each one. She walked me back, and that was super helpful.”</p> <p>“I think just be nice to people in general is important.”</p> <p>“I think that the nurses were very calm and respectful and were letting me experience my labor by myself with my husband.”</p> <p>“I think the support. It was the most important part.”</p> <p>“I think when I feel respected, it's just like people being like nice and fair.”</p> <p>“If you're demeaned or demoralized or infantilize through the process, it's going to be really hard to let your guard down and go through with it.”</p> <p>“In this area with our current technology being so prevalent, I was more concerned with just being treated well.”</p> <p>“It didn't feel super artificial, it just felt like loving .”</p> <p>“Just be nice with like a smile, it makes you feel really good.”</p> <p>“Just being encouraging.”</p> <p>“Kind of validating.”</p>		<ul style="list-style-type: none"> <li>• Consists of “Kindness, Empathy, and Encouragement”, “Negativity”, and “Positivity”</li> <li>• “Kindness, Empathy, and Encouragement” built from in vivo codes “Kindness,” “Empathy” and “Encouragement”</li> <li>• Philosophy, religion, midwifery, nursing</li> <li>• Vulnerability Theory</li> <li>• Welcoming atmosphere set the tone for the experience</li> <li>• Demeanor of the staff defined whether experience was positive or negative</li> <li>• General human decency has a profound effect on the experience</li> </ul>

<p>“Knowing their name, knocking in the middle of the night, not just going in and turning the lights on the night shift.”</p> <p>“Making me feel like you want me here.”</p> <p>“So, she like would talk me through like kind of like the pain.”</p> <p>“That reinforcement felt very personalized and like she cared about me as a human being.”</p> <p>“Validation”</p>		
<p><b>Empathy</b></p> <p>“I think if you can go somewhere where you can make a connection with the midwife, is probably the best.”</p> <p>“She was, she just hugged me and said it’s ok to cry.”</p> <p>“She gave me permission to be like, "No, I just had major surgery and this painful."</p> <p>“I think maybe just for them to have an understanding that, you know, that world is not everyone else's daily world, and so, seeing machines and people in scrubs and that can be traumatizing.”</p> <p>“I think just taking the extra time to be really kind and nice and empathetic goes a long way.”</p>		
<p><b>Encouragement</b></p> <p>“They were all very good at giving me praise and like positive feedback and stuff.”</p>		



<p>“The nurse would massage my back or even just rub my shoulders when I vomited and get me a cloth and say you are doing ok and this is all normal.”</p> <p>“The best thing was the encouragement.</p> <p>“The encouragement was helpful, even though I felt like I wasn't doing a good job.”</p> <p>“The midwife came in and started telling me what a great job I was doing and how strong I was and that felt good.”</p>		
<p><b>Negativity</b></p> <p>“Everyone [was] yelling and telling me to push and counting and it just felt, very pandemonium.”</p> <p>“I felt like a kid getting in trouble for not following the rules.”</p> <p>“I just know her body language was extremely closed.”</p> <p>“I was afraid that I would be made to feel like I have to do things, and that would be disrespectful to me.”</p> <p>“I was trying to like focus on the pain and the job at hand and they were just shouting at me.”</p> <p>“One started asking me, berating me sort of, about why I had not called. And yeah, it felt kind of bad, and sort of like a child.”</p>	<p><b>Negativity (n=18 statements)</b></p>	

<p>“She kept telling me I wasn't really in labor.”</p> <p>“She said my labor was dysfunctional.”</p> <p>“She said you can push your baby out with your next contraction or I’m giving you a episiotomy.”</p> <p>“She was super snippy and just gave no detail what so ever.”</p> <p>“Some of the nurses were a little bit tough love.”</p> <p>“The language that I wanted used was not used.”</p> <p>“The nurse kept saying my contractions weren't registering on the monitor. I was like, well I feel them.”</p> <p>“There was shouting and it uh seemed like some panic.”</p> <p>“There was so many people and I even told them. I was like, everybody's yelling at me. I need one person to talk to me.”</p> <p>“I was just kind of taken aback by like - even going upstairs when we like arrived to the nurse’s station just almost people had like the blank stare or something.”</p> <p>“When I came if they had been very welcoming it would make me at ease.”</p> <p>“Your baby is not gaining and I was worried and also felt like, I just failed and there was little help.”</p>		
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<p><b>Positivity</b></p> <p>“Everybody was really, really great.”</p> <p>“I just listened to the professionals and felt very well respected.”</p> <p>“My overall experience is positive.”</p> <p>“Pleasantly surprised would be how I'd describe it.”</p> <p>“The feeling I got was like I was just wasting her time and she couldn't be bothered to answer my question and I was annoying her. “</p> <p>“The pediatrician was kind of brisk with me.”</p> <p>“There was this idea that it is my baby and my body and my experience so I get a say. That was powerful.”</p> <p>“They really had things they said and did that made me feel good and supported.”</p> <p>“[they] tried their best to respect my wishes for sure.”</p> <p>“Women need to have a friendly face and support and feel cared for.”</p>	<p><b>Positivity</b> <b>(n= 12 statements)</b></p>	

<p>“You need someone who is emotionally keyed in, has all the skills and intellect and is, you know, warm - preferably warm and a people person.”</p> <p>“You want help and someone warm and you know, to like give advice.”</p>		
<p><b>Caregivers are Knowledgeable</b></p> <p>"I want to go to the hospital and have somebody take care of me, and who knows what's going on."</p> <p>“Every single person I talked to had a different answer.</p> <p>“I can trust people who know how I can stay safe and keep my baby safe.”</p> <p>“I eventually got fed up with like having a different opinion from everybody.”</p> <p>“I feel like they knew what was going on and had all this experience and knowledge and I did not need to know everything going in, it was all okay and they had my back.”</p> <p>“I had a lot of different nurses and one would say one thing and another one another thing.”</p> <p>“I had taken the classes and but I still had no idea what I was doing.”</p>	<p><b>Caregivers are Knowledgeable (n= 13 statements)</b></p>	<p><b>Caregivers Are Experts</b></p> <ul style="list-style-type: none"> <li>• Consists of “Caregivers are Knowledgeable”, “Caregivers are Confident”, and Expectations vs Realities”</li> <li>• Evidence-Based Practice</li> <li>• Three Delays Model</li> <li>• How prepared a woman is for what the experience is going to be like can set proper expectations</li> </ul>

<p>I just felt like she knew what she was doing.”</p> <p>It was like every nurse had something different to say about going home and self-care.”</p> <p>“She was really good and gave good advice and that was very, comforting.”</p> <p>“She was really knowledgeable and really helpful.”</p> <p>“The nurses and the midwife were like telling me all this stuff that helps and just, it was good to feel like, you know they are on my side and want me to do well.”</p> <p>“They were saying all different things and I really wanted the clarity of just speaking to the expert.”</p>		
<p><b>Caregivers are Confident</b></p> <p>“I like fed off of her confidence.”</p> <p>“I just feel like they're confident, like I just felt like they were really experienced.”</p> <p>“She was just very positive and she was - I think she was so confident too.”</p>	<p><b>Caregivers are Confident</b> <b>(n=3 statements)</b></p>	
<p><b>Expectations vs Reality</b></p>	<p><b>Expectations vs Realities</b> <b>(n=18 statements)</b></p>	

<p>“Also I took a mindfulness class that enabled - helps kind of introduce me to the idea that I didn't really know - you know, you can't really control, you just have to surrender and keep breathing.”</p> <p>“I didn't expect her to be there that much, but I just expected her to maybe check in a little bit more frequently.”</p> <p>“I didn't want to be a bother.”</p> <p>“I didn't want to be asked if I wanted pain medication.”</p> <p>“I felt like the nurses more helped me deliver the baby than the midwife, which was kind of - I was a little surprised about, like we - she wasn't really around when I wanted to be checked.”</p> <p>“I think having a very detailed birth plan and clearly communicating to them that this is really important to me, and this is what I'm going to do, and I won't be wavering from it, and I don't want to be asked certain things.”</p> <p>“I understand that they're trained and - but, I knew enough to know that I don't have to do anything, it's all my choice.”</p> <p>“I was really nervous about because I had I guess what you'd call an alternative birth plan - a hypnobirth.”</p> <p>“I was really worried that I was going to be met with a lot of resistance and my concentration would have to be on convincing them that this is what I wanted.”</p> <p>“I was so nervous about how I would be treated and if I would be listened to.”</p> <p>“I was very untrusting at first.”</p>		
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<p>“I’ve been to see the doctor in other places in the county and I’ve never received any kind of personalized care like that. And it really - I feel like it really helped move my labor along to feel like I could trust this person.”</p> <p>“If I was made to feel like my choices weren't valid or safe. Or, when I know like the hospital was accepting of having a birth like mine, I think it would have been disrespectful if I had been met with resistance.”</p> <p>“It was a lot about like, you know, very holistic practices with a mesh of like western medicine that we like.”</p> <p>“It's so messed up how in the media like that like the squeezing someone's hand and screaming and, you know, grinding your teeth and all that stuff that people do on sitcoms, like I could definitely - I definitely wouldn't have been able to give birth if I was doing any of those things.”</p> <p>“Making me feel like I have to do things their way or a certain way because they feel that is the best way when it doesn't have to go that way.”</p> <p>“My sister-in-law had her midwife came to the house a couple of times post, and I thought that that was amazing, and I kind of thought that that was normal like for here. And I remember asking that the first time and I'm like, "What? You guys don't?"</p> <p>“You don’t always get that in healthcare these days so that was amazing.”</p>		
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<p><b>Safety and Cleanliness</b></p> <p>“A place that is clean and safe and that has you know, people who have the knowledge.”</p> <p>“I liked that I wasn't giving birth in a place where a lot of sick people were.”</p> <p>“I received really high quality care.”</p> <p>“I think it just feels like a safe, healthy, respectful place.”</p> <p>“I think safety I guess is like one of the things that is important to me, but also cleanliness and being comfortable.”</p> <p>“It felt very safe there.”</p> <p>“It just it felt like a safe, friendly, clean.”</p> <p>“The staff was great and everything was clean.”</p> <p>“They were safe and nice and respectful.”</p> <p>“When we first got there they had no room for us available, which we were told would like never happen, but it did happen.”</p> <p>“You have to build trust by knowing the place is safe and caring.”</p> <p>“You want all the medical stuff to be in place and to make sure that they have a good record.”</p>	<p><b>Safety and Cleanliness (n=12 statements)</b></p>	<p><b>The Environment is Safe</b></p> <ul style="list-style-type: none"> <li>• Consists of “Safety and Cleanliness” and “Comfort and a Good Environment.”</li> <li>• Women feel positive in an environment that is clean</li> <li>• Safety is an important factor in where to seek care</li> <li>• Feeds into future decision-making about place of birth</li> </ul>
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<p><b>Comfort and a Good Environment</b></p> <p>“I didn't get to use any of the options [such as the hot tub] really that I was hoping to, but knowing that they were there [was important].”</p> <p>“I liked that it felt more like a birthing center.”</p> <p>“I mean the unit is quiet, the rooms are big.”</p> <p>“It was like people in and out like every two minutes and there was a large group of like someone’s family right outside my room in the visitor area and it was distracting.”</p> <p>“You get your own suite and like and you get to stay in the same room as the baby.”</p>	<p><b>Comfort and a Good Environment</b> <b>(n=5 statements)</b></p>	